THE ECONOMIC COST OF CANCER IN ADOLESCENTS AND YOUNG ADULTS

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YOUTH CANCER SERVICE | canteen

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Glossary

ABS	Australian Bureau of Statistics
ACIM	Australian Cancer Incidence and Mortality
AIHW	Australian Institute of Health and Welfare
ALL	acute lymphoblastic leukaemia
AML	acute myeloid leukaemia
AYA	adolescents and young adults
DALY	disability-adjusted life year
DHS	Department of Human Services
DSP	Disability Support Pension
DSS	Department of Social Services
DWL	deadweight loss
HIV	human immunodeficiency virus
HL	Hodgkin lymphoma
NHL	non-Hodgkin lymphoma
NPV	net present value
NSA	Newstart Allowance
PBS	Pharmaceutical Benefits Scheme
SDAC	Survey of Disability, Ageing and Carers
SKA	Sickness Allowance
USA	United States of America
UV	ultraviolet
VSL	value of a statistical life
VSLY	value of a statistical life year
WHO	World Health Organization
WTP	willingness to pay
YLD	years of healthy life lost due to disability
YLL	years of life lost due to premature death
YLO	Youth Allowance

Executive Summary

Cancer in adolescents and young adults (AYAs) places a significant burden on the person with cancer, their carers, and the economy. Along with the pain and suffering of living with cancer, AYAs with cancer incur expenses to treat their cancer, forfeit income when they are unable to work, have diminished employment opportunities over the rest of their life, often rely on welfare payments, and in the worst cases will die prematurely as a result of cancer. Their primary carers, often their parents, will also experience a significant caring burden.

This report calculated the economic cost of cancer in AYAs (people aged 15-25 years old) diagnosed in 2016. The costs in this report are the lifetime costs experienced by the 2016 cohort of AYAs with cancer. While there are around 100 types of cancer, this report focuses on the ten types of cancer which are most commonly reported in AYAs.

It is estimated that **there will be almost 1,100 AYAs diagnosed with cancer in 2016**, of which melanoma will have the highest number of incident cases (approximately 194), followed by Hodgkin lymphoma (141) and testicular cancer (89). **There will be an estimated 112 AYAs who will die from cancer in 2016**. The highest mortality is expected among AYAs with brain cancer (20 deaths).

The total cost of cancer which was quantified for this report is made up of several components, including health system costs, productivity costs, informal care costs, dead weight losses and burden of disease costs. Please note that in addition to these costs there are additional costs which were not quantified, such as some education costs, presenteeism (reduced productivity while at work), health system costs that occur more than five years after diagnosis, government programs, formal care, travel, clinical trials, and funeral costs.

The lifetime cost of healthcare for AYAs diagnosed with cancer in 2016 was estimated to be $146.5 million. The largest component of health expenditure is for patients admitted to hospital at $129.1 million, followed by out-of-hospital expenditure ($15.2 million), and prescription pharmaceuticals ($2.2 million). **It was estimated that the total lifetime productivity costs will be $508.4 million**. This is comprised of costs from being temporarily absent from work ($2.8 million), leaving the workforce ($290.1 million), premature mortality ($162.0 million), informal care ($52.7 million), and other costs ($0.8 million). **There is also an associated deadweight loss (DWL) of $87.0 million**, as a result of reduced taxation revenue ($182.0 million), government health expenditure ($99.3 million) and welfare payments ($21.4 million). The economic **value of the burden of disease from all cancers in AYAs diagnosed in 2016 was estimated to be $701.4 million.**

For AYAs who are diagnosed with cancer in 2016, the total lifetime costs were estimated to be $1.4 billion, which is equivalent to $1.3 million per person: $0.6 million in burden of disease costs, and $0.7 million in health costs, productivity losses, informal care costs and DWLs.

1. Introduction

Deloitte Access Economics was commissioned by CanTeen to undertake an analysis of the economic cost of cancer in adolescents and young adults (AYAs) in 2016. For the purpose of this report, AYAs are defined as those people who are aged 15-25 years old in 2016.

The lived experience of cancer among AYAs is significantly different to people in older age groups. While AYAs have better overall rates of survival than other age groups (albeit lower survival observed for specific cancers), the number of years lived post-cancer is higher, resulting in the number of years impacted by their cancer also being higher. Additionally, as AYAs are diagnosed with cancer during high school and tertiary education years, the impact on educational outcomes can be significant, with the potential to negatively impact on future employment opportunities. Given their relatively younger age, AYAs are more likely to seek parental support, which places a significant burden on their parents. In addition to these, AYAs who die from cancer miss out on a larger proportion of average life expectancy, compared to an older person with cancer.

1.1 CANTEEN AND THE YOUTH CANCER SERVICE

CanTeen is a national support organisation for young people living with cancer, which was set up in 1985 by a group of young cancer patients. Support is offered to young people with cancer, as well as young people who have a parent with cancer, or whose sibling or parent has died due to cancer. CanTeen provides counselling and individual support, peer support programs, information and resources, and youth cancer services. They also undertake research and evaluation to enhance knowledge and understanding into the needs of young people living with cancer (CanTeen, 2016a).

A Youth Cancer Service operates out of five lead hospitals (tertiary hospitals in Sydney, Adelaide, Brisbane, Melbourne and Perth) and work with over 20 hospitals and health services in Australia. Youth Cancer Services provide specialist, age-appropriate treatment and support services for AYAs with cancer. Funding for Youth Cancer Services comes from the Federal Government and is administered by CanTeen (Youth Cancer Services, 2016). In four out of five jurisdictions, state and territory governments match the funding provided by CanTeen. The services are funded to provide support to every young cancer patient diagnosed across Australia, and requiring hospital-based treatment and support.

1.2 STRUCTURE OF THE REPORT

This report has been structured in the following manner:

- Chapter 2 provides a brief overview of cancer, including the definitions, diagnosis, complications and comorbidities, prognosis, treatment options, and the types of cancer discussed in this report.
- Chapter 3 discusses the approach taken to estimate the economic costs of cancer.
- Chapter 4 presents incidence and mortality estimates, and calculates active prevalence.
- Chapter 5 documents the costs of cancer to the health system by type of cost and affected stakeholder.
- Chapter 6 estimates the productivity costs of cancer.
- Chapter 7 summarises the transfer costs associated with cancer and calculates the resultant economic cost.
- Chapter 8 discusses and estimates the burden of disease costs of cancer.
- Chapter 9 summarises the total costs of cancer.

1.3 SCOPE OF COSTS INCLUDED IN THIS REPORT

The economic costs of cancer are many and varied. The scope of costs for this report has been limited to the following elements: health system costs, productivity costs (absenteeism, workforce participation, premature mortality, productivity-related administrative costs, and informal carer costs), deadweight losses (DWLs) and the burden of disease.

Costs which were considered to be out of scope for this report include educational impacts, presenteeism (reduced productivity while at work), health system costs that occur more than five years after diagnosis, government programs, formal care, travel, clinical trials[1] and funeral costs brought forward. In addition to these costs which were not quantified, this report uses a new methodology for calculating burden of disease losses, as recommended by the

Australian Institute of Health and Welfare (AIHW) and the World Health Organization (WHO). Further detail on this new methodology is provided in Chapter 9.

Given the scope of costs in this report, and changes to the burden of disease methodology, care should be taken in comparing costs in this report with costs calculated in prior burden of disease reports (for example, Access Economics' 2007 report for the Cancer Council of New South Wales).

This report calculated the cost of cancer for ten different types of cancer, and also for "other cancer" which covers the approximately 100 other less common types of cancer experienced by AYAs. Where possible, data for the calculations were sourced for each individual type of the ten cancers. However, due to data limitations some data were not available at the individual cancer level. Where this occurred, costs were attributed to each type of cancer based each cancer's share of incident cases in 2016. Methodological notes have been provided throughout the report to note where this has occurred.

[1]This study further excludes personal financial costs and potential health care savings (occurring in future years) associated with AYA recruitment into clinical trials. CanTeen has advised that recruitment to cancer research clinical trials for this age group is relatively low given the limited availability of suitable trials, and consequently this can result in large personal financial costs associated with travel abroad.

2. Cancer in Australia

This chapter provides a brief epidemiological overview of cancer, including causes, complications, comorbidities, prognosis, current treatment options, and a description of each of the cancers which are separately identified in this report.

2.1 WHAT IS CANCER

Cancer is a term used to describe a range of diseases that feature uncontrolled cell division that spreads into the surrounding tissues. Normally, cells divide and multiply in a controlled manner to form organs. Conversely, cancer is the result of an error in the cells' genetic blueprint, where the deoxyribonucleic acid (commonly known as "DNA") of the cell is adversely affected by a carcinogen[2] or is the product of a genetic mutation. This results in uncontrolled growth and division of cells in the body, resulting in what is known as a tumour. Large collections of these cancerous cells within the tumour continue to grow and can potentially spread to other parts of the body.

As cancer can affect the vast majority of cells within the human body, there are around 100 different forms of cancer that can affect an individual. A tumour is stated to be benign if it does not spread away from the immediate area in which the cancer cells form. Typically, when a benign tumour or cancer is removed it will not grow back, assuming that the entire tumour is removed. Conversely, malignant tumours spread to other parts of the body via the blood stream or the lymphatic system. When a malignant tumour spreads to other parts of the body, secondary cancers may form. This process is called metastasis (Cancer Council, 2016a).

Some areas of the body are more likely to be affected by cancer. This can be due to a site's cell multiplication rate, resulting in a higher risk of genetic mutation. Areas where there is a high cell multiplication rate include the skin, intestines and bone marrow. Areas of the body that have been exposed to carcinogens, such as the lungs, skin and liver, are also more likely to be afflicted. For cancers such as leukaemia, the site's increased likelihood of receiving abnormal cells from a primary site may also play a role (Preston-Martin et al, 1990).

2.2 DIAGNOSIS

Cancer can be diagnosed through multiple pathways: physical examination, blood test, urine test, biopsy, x-rays and other scans (including computed tomography scans, magnetic resonance imaging scans, ultrasound scans, bone scans, isotope scans, positron emission tomography scans and mammograms) (National Cancer Institute, 2015b). Confirmation of the type of cancer determines the treatment path that will be followed.

Diagnosis classifies cancer based on stages of severity ranking the size and spread of the cancer. The Tumour, Nodes and Metastases system is a commonly used staging system for classifying cancer. In this system, T is representative of the size of the primary tumour, numbered from 0 to 4 in increasing size.[3] N reflects the number of lymph nodes nearby that have cancer, rated from 0 to 3 in increasing order. Finally, M is representative of the degree of metastasis, rated from 0 (the cancer has not spread to other areas of the body) to 1 (the cancer has spread) (National Cancer Institute, 2015d).

Another method of describing cancer severity is based on a numerical classification broken up into five groups (National Cancer Institute, 2015c):

- Stage 0: Otherwise known as carcinoma in situ, abnormal cells are present however they have not spread to the surrounding tissue (i.e. the abnormal cells have the potential to become cancerous);
- Stage 1-3: A cancerous tumour is present – the higher the stage number the larger the tumour and the further it has spread into the surrounding tissue; and
- Stage 4: Distant and unrelated parts of the body have now been afflicted with the original tumour.

Alongside stages, cancers are also graded by considering the features of the tumour. This is used to determine how abnormal and how malignant the cancer cells are. Tumour grades range from grade one (least malignant with the best chance of long term survival) to grade four (most malignant). In grade four, cells have the ability to form new blood vessels to maintain their rapid growth. Grade is determined by looking at the abnormal cells under a microscope, however a range of cell grades can be present in a tumour at any given time (National Cancer Institute, 2015d).

2.3 COMPLICATIONS AN D COMORBIDITIES

A number of complications, comorbidities and late effects can surface from a cancer diagnosis. Common complications include the presence of pain, nausea, diarrhoea/constipation, weight loss, fatigue, brain and nervous system problems, a weakened immune system and other chemical changes within the body (American Cancer Society, 2016a).

Comorbidities may also arise from the cancer itself or from the side effects of cancer treatment. These can include cardiac complications, endocrinologic late effects, physical performance outcomes (particularly from central nervous system, bone and soft tissue cancers), neuro-cognitive outcomes, fertility, psychological distress and social outcomes.

Late effects of cancer may not appear until months or years post-treatment. A number of factors influence an individual's likelihood of developing late effects. The primary risk factors include: type and location of cancer; type and dosage frequency of treatment; age when receiving treatment; genetic predisposition; and pre-existing health problems (American Cancer Society, 2016d).

Presentation of these late effects can be either emotional or physical. Emotional effects include the development of depression and anxiety surrounding health conditions and the fear of cancer recurrence. There are a wide range of physical late effects that can affect children, including (Schwartz, 1999):

- development of a secondary cancer;
- endocrine system problems;
- reproductive and sexual development issues;
- heart problems;
- lung damage; and
- learning and memory problems.

Other types of late effects may develop depending on the area of the body receiving treatment. For example, AYAs that have received high doses of radiation to the head and neck are at higher risk of developing gum disease in future.

2.4 PROGNOSIS

A patient's prognosis is determined by a number of key factors including: location, type, stage, grade and traits of the cancer and its cancer cells (National Cancer Institute, 2014). The patient's age and prior health also plays a key role in determining the length of survival post diagnosis.

One method of determining prognosis is by looking at survival rates. Survival rates measure the survival of individuals diagnosed with cancer compared to the general population. Section 4.3 presents survival rates for 1, 2, 3, 4 and 5 years post diagnosis, broken down by gender and type of cancer.

2.5 TREATMENT OPTIONS

Due to the large amount of cancer groups and subgroups, there are a range of treatment options for cancer patients. However, treatment options depend on the type, location, stage and grade of the cancer. For some conditions there may only be one option for treatment. Due to the risk of negative side effects associated with cancer treatments, some individuals may choose to not participate in some or all forms of treatment. The typical forms of cancer treatment are described below, and a patient will typically receive more than one type of treatment (National Cancer Institute, 2015e).

Surgery involves a medical professional physically removing or de-bulking a cancer tumour. The purpose of doing this is to eliminate the tumour, ease cancer symptoms or slow the progression of the cancer by removing part of the tumour.

Radiation therapy (also known as radiotherapy) uses high doses of radiation to shrink tumours and kill cancer cells. This works to ease symptoms, slow or stop the growth of the tumour, prevent the tumour returning, or cure the condition completely. Normal cells that are exposed to the radiation are generally able to recover faster and better than the cancer cells. Side effects of radiation therapy include: hair loss, skin problems, fatigue, loss of appetite and diarrhoea.

[2]A carcinogen is any substance that is capable of causing cancer in living tissue (American Cancer Society, 2016c).
[3]An X result implies that the tumour/number of lymph nodes/level of metastasis cannot be measured.

Chemotherapy is a method of stopping or slowing the growth of cancer cells using medicines. It is also used to assist with other interventions or ease cancer symptoms. Chemotherapy medicines are designed to target fast growing cells. Unfortunately, cancer cells are not the only fast-growing cells in the human body, so normal fast growing cells such as hair, the intestines and the lining of the mouth can also be affected. Normal cells usually recover better than cancer cells. As chemotherapy targets fast-growing cells, major side effects often include hair loss, nausea and mouth sores. Other side effects include fatigue, muscle and nerve problems, blood disorders and vomiting.

Immunotherapy is a form of biological therapy that uses compounds derived from living organisms. These organisms assist in 'marking' cancer cells so the immune system can locate and destroy these normally hidden cells. Other forms of immunotherapy work to strengthen the immune system.

Targeted therapy involves the use of small-molecule medicines or monoclonal antibodies that are designed to target the specific changes to cancer cells that help them grow, multiply and spread. This type of treatment works to assist the immune system to: kill cancer cells, prevent the growth of cancer cells, deliver cell-destroying substances to the cells or starve the cells of the hormones they require to continue growing.

Endocrine therapy, or hormone therapy, is used to stop or slow the growth of cancers that require hormones to fully develop. These therapies stop the body from producing hormones. They can also interfere with the behaviour of hormones in the body.

In addition to these treatment options, **complementary therapies** such as meditating, diet changes, counselling and exercises can be undertaken by individuals to address overall wellbeing. These therapies can also be used to address key risk factors, reduce stress and reduce the severity of side effects (National Cancer Institute, 2015e).

As technology advances, **personalised medicine** will become increasingly utilised by health professionals. Personalised medicine involves the optimal selection of treatment based on an individual's genetic makeup. In this vein, cancer treatments will be grouped based on the genetic changes to a tumour, rather than the stage, grade and type of tumour (Jackson and Chester, 2015).

2.6 TYPES OF CANCER DISCUSSED IN THIS REPORT

This report estimates economic costs for ten separate types of cancers (selected due to their relatively higher occurrence in AYAs), in addition to the costs of all cancers combined (i.e. these ten plus other types of cancer in AYAs). Information regarding each of these cancers is presented below.

2.6.1 Melanoma

Melanoma is a cancer of the melanocytes (pigment-containing cells) that often arises from overexposure to ultraviolet (UV) light. Typically, melanoma is a cancer of the skin however it has also been known to appear in the eye. In rare instances, melanomas can develop in areas of the body that have never been exposed to the sun, such as the mouth and intestines (Cancer Council, 2016b).

Often there are no symptoms associated with the onset of melanoma, aside from changes to the site itself or dark areas under nails or membranes in the mouth, anus or vagina. Risk factors include the presence of a large number of moles, genetic predisposition, long periods spent in UV light and poor immune function (Cancer Council, 2016b).

2.6.2 Haematological cancers

This report discusses four types of haematological cancers listed below.

Acute myeloid leukaemia (AML) is representative of a group of leukaemias that form in the myeloid blood cells in bone marrow. It occurs when there is an overproduction of immature white blood cells, also known as myeloblasts. As they are immature, these cells are inadequate for preventing the development of infection. Uncontrolled growth of these cells can flow into the blood stream, crowding bone marrow. This inhibits the development of normal blood cells (Leukaemia Foundation, 2016a).

Acute lymphoblastic leukaemia (ALL) similarly involves the overproduction of immature white blood cells, also known as lymphoblasts. Uncontrolled growth of lymphoblasts lowers the healthy white blood cell count, resulting in a reduced ability to fight infection. It also prevents the bone marrow from producing normal blood cells due to overcrowding at the site. Lymphoblasts can also spread to other organs and sites within the body (Leukaemia Foundation, 2016b).

Side effects for AML and ALL often involve patients becoming anaemic due to a low level of red blood cells and platelets. The main risk factors for AML and ALL include: genetic predisposition, chemical exposure, radiation exposure and previous experience with pre-leukemic blood disorders (Leukaemia Foundation 2016a; Leukaemia Foundation 2016b).

Non-Hodgkin lymphoma (NHL) is a cancer of the lymphatic system, involving B and T-cell lymphomas. When B and T-lymphocytes begin to grow uncontrollably after a malignant change, lymphomas develop. These lymphomas form tumours in the lymph nodes and other parts of the body. Generally speaking, the majority of lymphomas develop from malignant B-lymphocytes. Key risk factors for NHL include genetic predisposition, having a weak immune system, or the presence of an infection (Cancer Council, 2016c; Leukaemia Foundation, 2016c).

Hodgkin lymphoma (HL) is another cancer of the lymphatic system involving the uncontrolled growth of malignant lymphocytes. These malignant lymphocytes form tumours in lymph nodes and other sites across the body. Separate to other forms of lymphoma, HL is characterised by multinucleated Reed-Sternberg cells. Prior contraction of the Epstein-Barr virus has been connected with the development of HL, however the primary cause of the disease has not been identified. Other risk factors include genetic predisposition, having a weak immune system, human immunodeficiency virus (HIV) infection, or use of certain medicines used to prevent organ rejection during organ transplants (Leukaemia Foundation, 2016d).

2.6.3 Brain cancer

Brain cancer, otherwise known as intracranial neoplasm, is the result of uncontrolled, abnormal cell growth within the brain. There are more than 130 types of brain tumour that can be either malignant or benign (Cure Brain Cancer Foundation, 2016). Brain tumours are particularly dangerous as they can place pressure on the brain or even shift it closer to the skull. Nerves and healthy brain tissue may become compromised as a result of this. Risk factors include genetic predisposition (including neurofibromatosis), exposure to chemicals, contraction of the Epstein-Barr virus and exposure of high doses of radiation to the head (Cancer Council, 2016d).

2.6.4 Bone cancer

Also known as bone sarcoma, bone cancer involves the neoplastic growth of tissue in bone, resulting in a tumour. Primary bone tumours originate in the bone from bone cells and tissues. Metastatic tumours spread from other areas of the body to the bone tissue. There are three main types of bone sarcoma (Cancer Council, 2016e) including:

- osteosarcoma, which affects the cells that grow bone tissue;
- chondrosarcoma, which affects growth in cartilage; and
- Ewing's sarcoma, which affects cells in the bone that are prone to uncontrolled multiplication.

Risk factors for bone cancer include genetic disorders, Paget disease, exposure to radiation and bone marrow transplantation (osteosarcoma only).

2.6.5 Soft tissue cancer

Soft tissue cancer, or soft tissue sarcoma, forms in the body's connective tissue and other soft tissue (such as fat, muscles and nerves) throughout the body. Not all types of soft tissue sarcoma are cancerous, with some intermediate soft tissue sarcomas being neither malignant nor benign. No primary risk factors for this type of cancer have been identified (American Cancer Society, 2016b).

2.6.6 Testicular cancer

Testicular cancer involves the uncontrolled division and growth of germ cells in the testes. Typically, testicular cancer occurs in one testicle but occasionally it can occur in both. In malignant cases of testicular cancer, the cancer can spread to nearby lymph nodes or other areas of the body. Primary risk factors include genetic predisposition, an undescended testicle, HIV infection, ethnicity, weight and exposure to carcinogens (Cancer Council, 2016f).

2.6.7 Thyroid cancer

Thyroid cancer occurs when there is uncontrolled growth and division of the follicular or parafollicular thyroid cells. There are four main types of thyroid cancer including papillary (the most common type of thyroid cancer), follicular, medullary, and anaplastic. Primary risk factors for thyroid cancer include a genetic predisposition to the condition, exposure to radiation and other genetic conditions (Cancer Australia, 2015).

3. Estimating the economic costs of cancer

This chapter describes the approach taken to estimate the economic costs of cancer in AYAs, and outlines some of the key economic terms, how costs are borne by members of society, and some of the underlying methodology present throughout the following chapters. Specific methodologies for each of the costs associated with cancer are outlined further in the chapter where they are discussed.

3.1 INCIDENCE AND PREVALENCE APPROACHES

This report utilises an **incidence (lifetime costs) approach** to estimate the costs of cancer in AYAs for the year 2016. The alternative approach is the prevalence (annual cost) approach. The difference between incidence and prevalence approaches is illustrated in Figure 3.1.

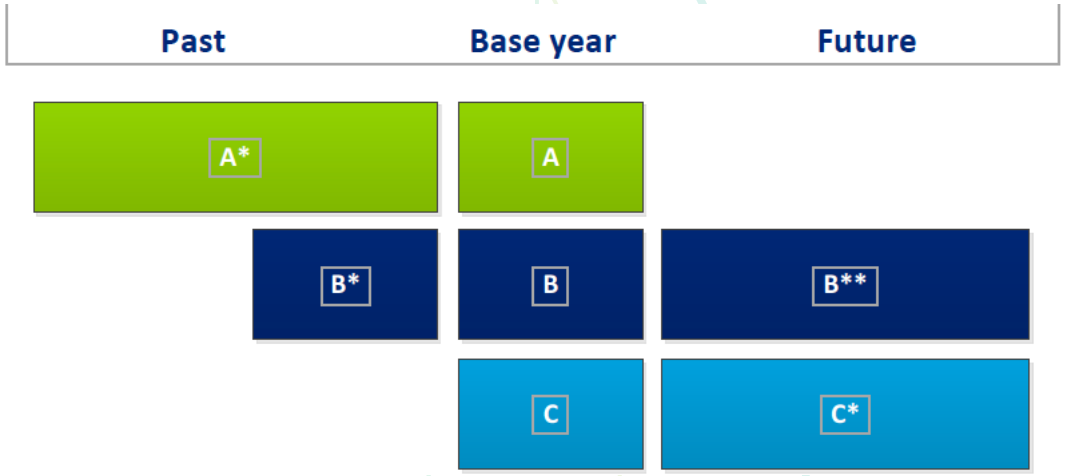
Consider three different cases of people with cancer:

- a, who was diagnosed with cancer in the past and has incurred the associated costs up to the year in question, with associated lifetime costs of A + A*, shaded in green;
- b, who was diagnosed with cancer in the past and has incurred the associated costs in 2016 as well as in the past and future, with associated lifetime costs of B + B* + B**, shaded in dark blue; and
- c, who was diagnosed with cancer in 2016, with lifetime costs of C + C*, shaded in light blue.

All costs should be expressed as present values relative to 2016:

- Annual prevalence-based costs in the base year = Σ(A + B + C);
- Annual incidence-based costs in the base year = Σ(C + present value of C*)

Figure 3.1: Incidence and prevalence approaches to measurement of costs



Source: Deloitte Access Economics.

Note that Figure 3.1 also defines the lifetime costs of cancer for each person, as follows:

- Lifetime cost for person c (= Incidence cost) = C + present value of C*
- Lifetime cost for person b = B + present values of B* and B**
- Lifetime cost for person a = A + present value of A*

Using an incidence approach, only cases like 'c' would be included, with the total cost estimate equivalent to the sum of all the costs in the base year (ΣC) plus the present value of all the future costs (ΣC*). Costs associated with people with cancer diagnosed in an earlier year would be excluded.

Using a prevalence approach, costs in 2016 relating to a, b and c would all be included, with total costs equal to Σ(A + B + C). Costs in all other years are excluded.

3.2 CLASSIFICATION OF COSTS

There are five types of costs associated with cancer.

- Direct financial costs to the Australian health system include the costs of running hospitals and other facilities (buildings, care, consumables), general practitioner and specialist services reimbursed through Medicare and private funds, the cost of pharmaceuticals (Pharmaceutical Benefits Scheme (PBS) and private) and of over-the- counter medications, allied health services, research and "other" direct costs (such as health administration).
- Productivity costs include productivity losses of the people with cancer, premature mortality and the value of informal care (including lost income of carers). Note that presenteeism (costs associated with reduced productivity while at work, due to cancer) have not been included in this analysis due to limited age-specific data.
- Administrative costs and other financial costs include government and non- government programs such as respite, community palliative care, out-of-pocket expenses (such as formal care, aids, equipment and modifications that are required to help cope with illness, and transport and accommodation costs associated with receiving treatment), and funeral costs. Note that these costs are beyond the scope of this report and have not been included.
- Transfer costs comprise the DWLs associated with government transfers such as taxation revenue foregone, welfare and disability payments.
- Non-financial costs are also very important — the pain, suffering and premature death that result from cancer. Although more difficult to measure, these can be analysed in terms of the years of healthy life lost, both quantitatively and qualitatively, known as the "burden of disease".

Different costs of disease are borne by different individuals or sectors of society. Clearly the people with cancer bear costs, but so do employers, government, friends and family, co-workers, charities, community groups and other members of society.

It is important to understand how the costs are shared in order to make informed decisions regarding interventions. While the people with cancer will usually be the most severely affected party, other family members and society (more broadly) also face costs as a result of cancer. From the employer's perspective, depending on the impact of cancer, work loss or absenteeism will lead to costs such as higher wages (that is, accessing skilled replacement short-term labour) or alternatively lost production, idle assets and other non-wage costs. Employers might also face costs such as rehiring, retraining and workers' compensation.

While it may be convenient to think of these costs as being purely borne by the employer, in reality they may eventually be passed on to end consumers in the form of higher prices for goods and services. Similarly, for the costs associated with the health system and community services, although the Government meets this cost, taxpayers (society) are the ultimate source of funds. However, for the purpose of this analysis, a 'who writes the cheque' approach is adopted, falling short of delving into second round or longer term dynamic impacts.

Society bears both the resource cost of providing services to people with cancer, and also the 'deadweight' losses (or reduced economic efficiency) associated with the need to raise additional taxation to fund the provision of services and income support.

Typically six groups who bear costs and pay or receive transfer payments are identified, namely the:

- people with cancer;
- friends and family (including informal carers); } The household
- employers;
- Federal Government;
- jurisdictional and local governments; and
- the rest of society (non-government, not-for-profit organisations, private health insurers, workers' compensation groups, and so on).

Classifying costs by five cost categories and allocating them to six groups enables a framework for analysis of these data to isolate the impacts on the various groups affected by cancer. This includes different levels of government, the business sector and community groups.

3.3 NET PRESENT VALUE

Where future costs are ascribed to the year 2016 throughout the report the formula for calculating the net present value (NPV) of those cost streams is:

$$NPV = \frac{\sum_{i=0}^{n} C_i}{(1+r)^i}$$

Where:

C_i = *cost in year i*

n = *years that costs are incurred*

r = *discount rate.*

Choosing an appropriate discount rate is a subject of some debate, as it varies depending on what type of future income or cost stream is being considered. The discount rate should take into consideration risks, inflation and positive time preference.

Generally, the minimum option that one can adopt in discounting future streams is to set future values on the basis of a risk free assessment about the future that assumes the future flows would be similar to the almost certain flows attaching to a long-term Government bond. Another factor to consider is inflation (price increases[4]), so that a real rather than nominal discount rate is used. If there is no positive time preference, the real long term government bond yield indicates that individuals will be indifferent between having something now and in the future. In general, however, people prefer immediacy, and there are different levels of risk and different rates of price increases across different cost streams.

Taking inflation, risk and positive time preference into consideration, a real discount rate of 3% is traditionally used, and this rate has been used in discounting cost streams in this report.

[4]The Reserve Bank has a clear mandate to pursue a monetary policy that delivers 2% to 3% inflation over the course of the economic cycle. This is a realistic longer run goal and a consumer price inflation rate of around 2.5% per annum on average has been achieved over recent years.

4. Incidence and mortality

This chapter outlines the incidence and mortality estimates for cancer in AYAs in Australia, estimates the five-year survival for the 2016 cohort, and calculates the number of AYAs with cancer from the 2016 cohort who will continue to incur costs over the next five years.

Key findings

There will be almost 1,100 AYAs diagnosed with cancer in 2016. Of the cancers separately identified in this report, melanoma will have the highest number of incident cases (approximately 194), followed by HL (141) and testicular cancer (89).

In the 15-19 age group, HL has the highest incidence rate (3.8 per 100,000). In the 20-24 age group, melanoma has the highest incidence rate (7.5 per 100,000). (Incidence for 25 year olds was based on rates in the 20-24 age group).

There were estimated to be approximately 112 AYAs who will die from cancer in 2016. The highest mortality is among AYAs with brain cancer (20 deaths).

Brain cancer has the highest mortality rate among those aged 15-19 (0.6 per 100,000), while bone cancer has the highest mortality rate among those aged 20-24 (0.6 per 100,000). Thyroid cancer had the lowest mortality rate in both age groups.

Among people aged 15-29, AML has the lowest five-year relative survival rate (76.5% at one year and 61.3% at five years), while thyroid cancer has the highest relative survival rate (99.7% at both one year and five year).

The 'active prevalence', as defined in Section 4.3, for AYAs was highest for melanoma at 205, followed by HL with 151 cases

4.1 INCIDENCE

Incidence is the number of newly diagnosed cases of cancer in a population in a specified time period. As cancer is a notifiable disease in Australia, it is a legal requirement in all state and territory legislation to report and record all new diagnosed cases of cancer. Data on diagnosed cancer cases in this report were sourced from the most recent AIHW Australian Cancer Incidence and Mortality (ACIM) books (AIHW, 2016a) and were used to calculate the expected incidence of cancer in 2016. The source of the ACIM incidence data was the Australian Cancer Database, which is compiled by the AIHW from state and territory cancer registries.

The incidence rates for each type of cancer in males and females aged 15-19 and 20-24 were calculated using age-gender specific incidence rates. As the AIHW incidence statistics do not include specific data for the 25 year old age group, incidence for 25 year olds was based on the incidence in the 20-24 age category, and this is shown in Table 4.2.

To calculate incidence, the average count of diagnosed cancer cases in the five most recent available years (2008-2012) was divided by the five year average estimated male and female population of those years. A five year average was calculated as there is significant year on year variation in diagnosed cases. Table 4.1 shows the estimated average annual incidence rate per 100,000 male and female AYAs in 2016.

Table 4.1: Estimated incidences rates, per 100,000 AYAs (15-24 years)

Cancer Type	Incidence rate 15-19		Incidence rate 20-24		Incidence rate 15-24	
	Male	*Female*	*Male*	*Female*	*Male*	*Female*
Melanoma	2.90	2.88	5.91	9.09	4.47	6.12
AML	1.02	0.94	1.20	1.09	1.11	1.02
ALL	2.20	0.75	1.12	0.57	1.66	0.66
NHL	2.14	1.23	2.42	1.93	2.28	1.59
HL	3.65	3.90	4.23	4.16	3.95	4.22
Brain	1.73	1.24	1.78	1.24	1.76	1.24
Bone	2.34	0.89	1.11	0.52	1.28	0.69
Soft tissue	0.98	0.93	1.04	0.86	1.01	0.89
Testicular	3.65	0.00	10.22	0.00	7.30	0.00
Thyroid	0.83	2.74	1.13	5.16	0.98	4.00
Other	4.38	5.24	7.67	11.05	6.26	8.09
All Cancer	**25.81**	**20.74**	**37.82**	**35.66**	**32.07**	**28.53**

Source: Deloitte Access Economics calculations based on AIHW (2016a).

Of the cancers, the highest incidence rate for females in the 20-24 age category is for melanoma, with a rate of 9.1 per 100,000. In the 15-19 female age group, HL has the highest incidence rate at 3.9, followed by melanoma at 2.9. For males aged 20-24, testicular cancer has the highest incidence rate at 10.2 per 100,000, followed by melanoma at 5.9. Testicular cancer and HL have the equal highest incidence rate for males aged 15- 19, of 3.7 per 100,000.

Table 4.2 and Chart 4.1 show the estimated incidence of cancer in 2016. This is calculated using the incidence rates in Table 4.1 and the estimated population of AYAs in 2016 from the Australian Bureau of Statistics (ABS, 2015b).

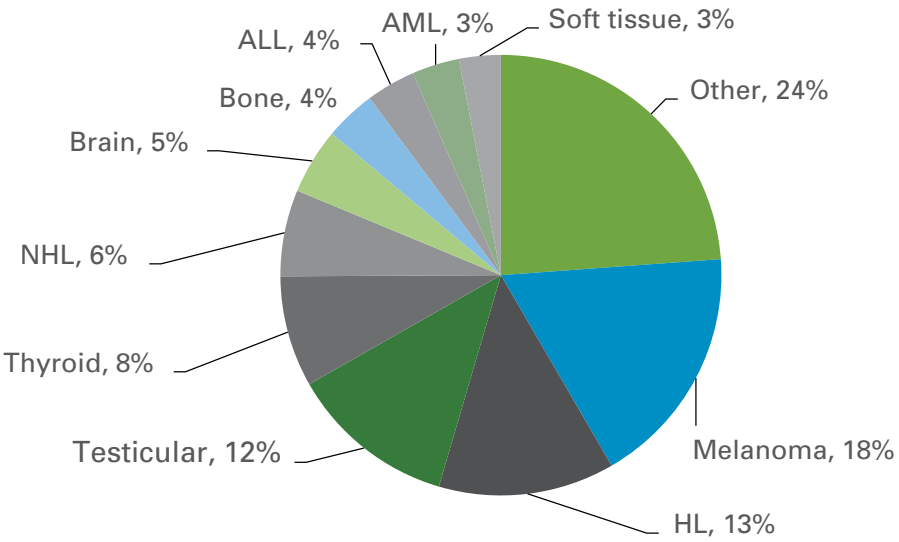
Table 4.2: Estimated incidence, 2016 (15-25 years)

Cancer type	Incidence		
	Male	*Female*	*People*
Melanoma	83	111	**194**
AML	20	18	**38**
ALL	28	11	**39**
NHL	41	28	**69**
HL	71	69	**141**
Brain	31	21	**53**
Bone	29	12	**41**
Soft tissue	18	15	**33**
Testicular	133	0	**133**
Thyroid	18	71	**89**
Other	112	147	**259**
All Cancer	**586**	**503**	**1,088**

Source: Deloitte Access Economics calculations based on AIHW (2016a).
Note: Numbers may not sum exactly to totals due to rounding.

As shown in Chart 4.1, the cancer with the highest incidence among AYAs in 2016 is melanoma (24%, 194 cases), followed by HL (13%, 141 cases), and testicular cancer (12%, 133 cases).

Chart 4.1: Distribution of cancer diagnoses, 2016



Source: Deloitte Access Economics calculations based on AIHW (2016a).

4.2 MORTALITY

Cancer mortality refers to the number of deaths due to cancer occurring in a specified population in a specified time period. Cancer mortality data in this report were sourced from the ACIM books. The source of the ACIM mortality data was the National Mortality

Database, which is compiled by the AIHW from state and territory Registries of Births, Deaths and Marriages and the National Coronial Information System.

The mortality rates of the categories of cancer in males and females aged 15-19 and 20-24 were calculated. As mortality statistics do not include specific data for the 25 year old age group, mortality for 25 year olds was based on rates in the 20-24 age category. To calculate cancer mortality, the average count of deaths due to cancer of the five most recently available years (2009-2013) was divided by the five year average estimated male and female population of those years (ABS, 2015b).

Table 4.3 shows the estimated mortality rate per 100,000 among AYAs with cancer in 2016.

Table 4.3: Estimated mortality rates, per 100,000 AYAs (15-24 years)

Cancer Type	Mortality rate 15-19		Mortality rate 20-24		Mortality rate 15-24	
	Male	*Female*	*Male*	*Female*	*Male*	*Female*
Melanoma	0.05	0.00	0.07	0.25	0.06	0.13
AML	0.24	0.28	0.27	0.18	0.25	0.23
ALL	0.80	0.34	0.34	0.20	0.56	0.27
NHL	0.11	0.14	0.10	0.05	0.10	0.09
HL	0.03	0.06	0.15	0.25	0.09	0.16
Brain	0.80	0.48	0.70	0.28	0.75	0.37
Bone	0.69	0.34	0.75	0.33	0.72	0.33
Soft tssue	0.13	0.39	0.24	0.20	0.19	0.29
Testicular	0.05	0.00	0.15	0.00	0.10	0.00
Thyroid	0.00	0.00	0.00	0.00	0.00	0.00
Other	0.56	0.62	0.75	1.32	0.66	0.99
All Cancer	**3.46**	**2.65**	**3.51**	**3.08**	**3.49**	**2.87**

Source: Deloitte Access Economics calculations based on AIHW (2016a).

The mortality rates were applied against the 2016 population of males and females aged 15-19, 20-24 and 25. Table 4.4 shows the estimated number of AYAs who are expected to die from cancer in 2016.

Table 4.4: Estimated mortality from cancer, 2016 (15-25 years)

Cancer type	Mortality		
	Male	*Female*	*People*
Melanoma	1	3	**4**
AML	5	4	**8**
ALL	10	4	**14**
NHL	2	2	**3**
HL	2	3	**5**
Brain	13	6	**20**
Bone	13	6	**19**
Soft tssue	4	5	**8**
Testicular	2	0	**2**
Thyroid	0	0	**0**
Other	12	18	**30**
All Cancer	**63**	**50**	**112**

Note: Numbers may not sum exactly to totals due to rounding.

4.3 ACTIVE PREVALENCE

As this report is using an incidence approach to calculate economic costs, it was necessary to calculate the number of AYAs diagnosed with cancer in 2016 who will continue to incur costs from their cancer in future years. Incident cases form the 2016 cohort who continue to incur costs in future years are referred to in this report as "active" cases.

Calculating the number of cases from the 2016 cohort who are still active in future years is complex, as it depends on defining a timeframe of remission after which cancer survivors are considered 'cured' and no longer living with cancer, and thus no longer incurring costs. Consistent with the methods used in Access Economics (2007) and Brameld et al (2002), active cases in future years were assumed to be incident cases from the 2016 cohort who will die within the next five years, but have not died yet. For example, active cases in 2017 are AYAs from the 2016 cohort who are expected to die between 2017-2020. AYAs with cancer who survive beyond five years are considered to be cured.

To calculate active cases, it was necessary to know the relative survival rates of AYAs from the 2016 cohort. These were then combined with mortality estimates for both the general population and the population with cancer, and used to calculate deaths from cancer in each of the next five years.

4.3.1 Relative survival rates

Relative survival rates are a measure of the survival of people diagnosed with cancer compared with that of the general population. Rates were sourced from the AIHW (2011). Due to limitations in the data, one and five year survival rates for people aged 15-29 years were used, and it was assumed that this represented a reasonable approximation of survival rates in AYAs. Survival rates for years two, three and four were adapted from AIHW (2012), which provides rates for people aged 0-39 with cancer, by applying the ratios of the rates in the intervening years against the 'bookend rates' for 15-29 year olds. One and five year data were not disaggregated by gender, however data for the intervening years were disaggregated by gender.

Two, three and four year survival rates for 0-39 year olds for ALL, bone cancer and soft tissue cancers were not available, so the average survival rates across all types of cancer (sourced from AIHW, 2012) were used for these cancers instead. The survival rate for 'central nervous system cancers' was used for brain cancer. Table 4.5 shows the estimated survival rates for AYAs, disaggregated by gender and type of cancer.

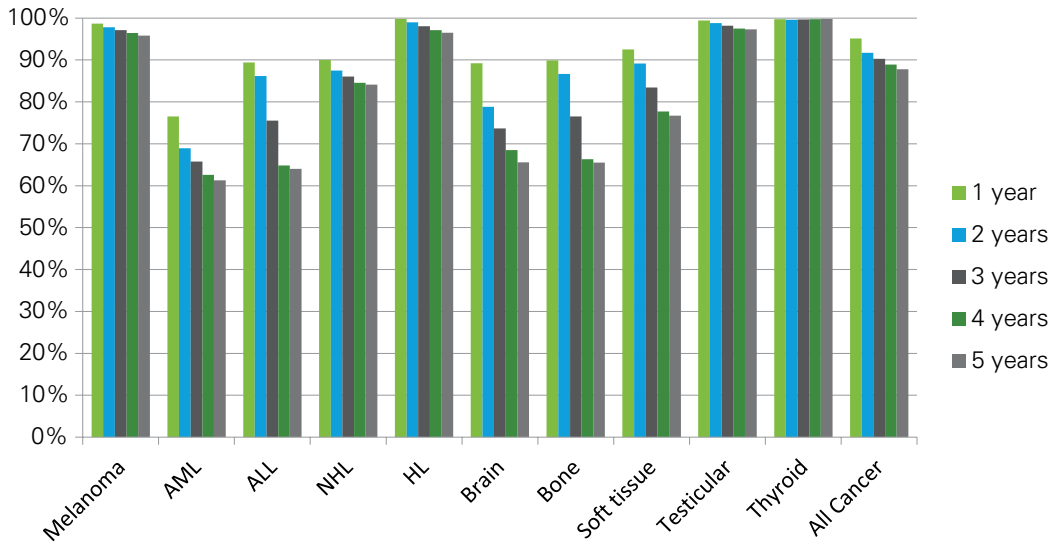
Table 4.5: Estimated relative survival rates 1-5 years after diagnosis (15-24 years)

Cancer type	1 year			2 years			3 years			4 years			5 years		
	Male	*Female*	*Person*	*Male*	*Female*	*Person*	*Male*	*Female*	*Person*	*Male*	*Female*	*Person*	*Male*	*Female*	*Person*
Melanoma	98.7%	98.7%	98.7%	97.7%	97.9%	97.8%	97.1%	97.1%	97.1%	96.4%	96.3%	96.4%	95.8%	95.8%	95.8%
AML	76.5%	76.5%	76.5%	70.1%	67.7%	68.9%	66.2%	65.2%	65.8%	62.4%	62.8%	62.6%	61.3%	61.3%	61.3%
ALL	89.4%	89.4%	89.4%	85.9%	86.4%	86.2%	75.3%	75.7%	75.5%	64.6%	65.0%	64.8%	64.0%	64.0%	64.0%
NHL	90.0%	90.0%	90.0%	87.2%	88.0%	87.5%	85.8%	86.4%	86.0%	84.5%	84.8%	84.6%	84.1%	84.1%	84.1%
HL	99.8%	99.8%	99.8%	98.7%	99.4%	99.0%	98.0%	98.1%	98.0%	97.3%	96.9%	97.1%	96.5%	96.5%	96.5%
Brain	89.2%	89.2%	89.2%	76.3%	82.1%	78.9%	72.5%	75.2%	73.7%	68.7%	68.3%	68.5%	65.6%	65.6%	65.6%
Bone	89.9%	89.9%	89.9%	86.4%	86.9%	86.7%	76.3%	76.7%	76.5%	66.1%	66.6%	66.3%	65.5%	65.5%	65.5%
Soft tissue	92.5%	92.5%	92.5%	88.9%	89.4%	89.2%	83.2%	83.7%	83.4%	77.4%	77.9%	77.7%	76.7%	76.7%	76.7%
Testicular	99.4%	-	99.4%	98.8%	-	98.8%	98.1%	-	98.1%	97.5%	-	97.5%	97.3%	-	97.3%
Thyroid	99.7%	99.7%	99.7%	99.2%	99.8%	99.6%	99.4%	99.8%	99.7%	99.7%	99.8%	99.7%	99.8%	99.8%	99.8%
All Cancer	**95.1%**	**95.1%**	**95.1%**	**91.4%**	**91.9%**	**91.7%**	**90.0%**	**90.6%**	**90.3%**	**89.2%**	**89.2%**	**88.9%**	**87.8%**	**87.8%**	**87.8%**

Source: Deloitte Access Economics calculations based on AIHW (2011) and AIHW (2012).

Chart 4.2 shows the relative survival rates from Table 4.5. AML, ALL, brain cancer and bone cancer have the lowest survival rates, which is also reflected in the mortality rates of these cancers. While these cancer types do not have the highest incidence, they do have high mortality rates.

Chart 4.2: Relative survival rates, by type of cancer



Source: Deloitte Access Economics calculations based on AIHW (2011) and AIHW (2012).

4.3.2 Active cases from the 2016 cohort

Using the incidence, mortality and relative survival estimates, Table 4.6 shows the incident cases from 2016, and the number of these cases that will still be active in each of the next five years. These results underpin all calculations of economic costs presented in this report.

Brameld et al (2002) has demonstrated that the sum of incidence in a given year and the sum of active cases in each of the next five years is a reasonable approximation of the "active prevalence" of cancer for the given year, i.e. the number of people who are receiving treatment for cancer in 2016. Thus, the number of AYAs with cancer who are receiving care for their cancer in 2016 was estimated to be 1,249, as shown in Table 4.6. This includes incident cases from 2016, as well as incident cases from prior years who are continuing to receive treatment for their cancer in 2016.

Table 4.6: Estimated incidence, active cases and active prevalence (15-25 years)

Cancer type	Incident cases 2016		Active prevalence								Total		
			2017		2018		2019		2020				
	Male	*Female*	*Male*	*Female*	*Male*	*Female*	*Male*	*Female*	*Male*	*Female*	*Male*	*Female*	*People*
Melanoma	83	111	2	4	1	2	1	1	1	1	88	119	**206**
AML	20	18	3	3	1	1	1	1	0	1	25	23	**48**
ALL	28	11	7	3	4	2	2	1	0	0	41	18	**59**
NHL	41	28	2	2	1	1	1	1	0	0	45	32	**77**
HL	71	69	2	3	1	2	1	1	1	1	76	75	**151**
Brain	31	21	7	6	2	3	2	2	1	1	43	33	**77**
Bone	29	12	7	3	4	2	2	1	0	0	42	18	**61**
Soft tissue	18	15	3	3	1	2	1	1	0	0	23	21	**44**
Testicular	133	0	3	0	1	0	1	0	0	0	138	0	**138**
Thyroid	18	71	0	0	0	0	0	0	0	0	18	71	**89**
Other	112	147	8	11	4	6	3	4	1	2	128	170	**298**
All Cancer	**586**	**503**	**43**	**37**	**21**	**21**	**13**	**14**	**5**	**7**	**668**	**581**	**1,249**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

5. Health system costs

This chapter outlines the total health system costs associated with cancer, and provides a breakdown by type of cost into in-hospital, out-of-hospital, and pharmaceuticals.

Key findings

The lifetime cost of healthcare for AYAs diagnosed with cancer in 2016 was estimated to be $146.5 million ($135,000 per person), in 2016 dollars.

The largest component of health expenditure was for admitted patients ($129.1 million), followed by out-of-hospital expenditure ($15.2 million), and prescription pharmaceuticals ($2.2 million).

5.1 TOTAL HEALTH SYSTEM COSTS

The primary source for health expenditure data in this report was the AIHW's report on health system expenditure on cancer and other neoplasms in Australia in 2008-2009 (AIHW, 2013). This report provides data for six cancer categories with the highest health system expenditure, disaggregated by gender and the 15-24 age group.[5] AIHW (2013) notes that the distribution of health system expenditure for cancer is different to that for all chronic diseases. Hospital admitted patient services form a significantly larger proportion of health costs for cancer – 79% for all cancer in all ages compared to 59% for all chronic diseases. As a result, expenditures for out-of-hospital services and prescription pharmaceuticals are much lower compared to all chronic diseases (9% vs. 24% and 12% vs. 16%, respectively).
This is reflected in expenditure in the AYA age category, where admitted hospital costs are the largest component of health expenditure.

Due to gaps in the data, some assumptions were made in calculating health system expenditure. The AIHW report does not provide expenditure data for NHL in females, and so the per person cost for males was used for females as well. Similarly, expenditure data for thyroid cancer in males were not available, so the per person cost of thyroid cancer in females was also used for males. Expenditure data for melanoma in 2008-2009 were not available, so expenditure data for melanoma in 2001 were used (AIHW, 2005), and updated to 2016 based on health inflation and changes in age-gender incidence rates.

In addition to AML and ALL which are included in this report, there are two other main forms of leukaemia; chronic lymphocytic leukaemia and chronic myeloid leukaemia. The AIHW (2013) report included expenditure for all subtypes of leukaemia combined. Incidence data from the AIHW (2016a) ACIM books were used to approximate the amount of health system expenditure that could be attributed to AML and ALL.

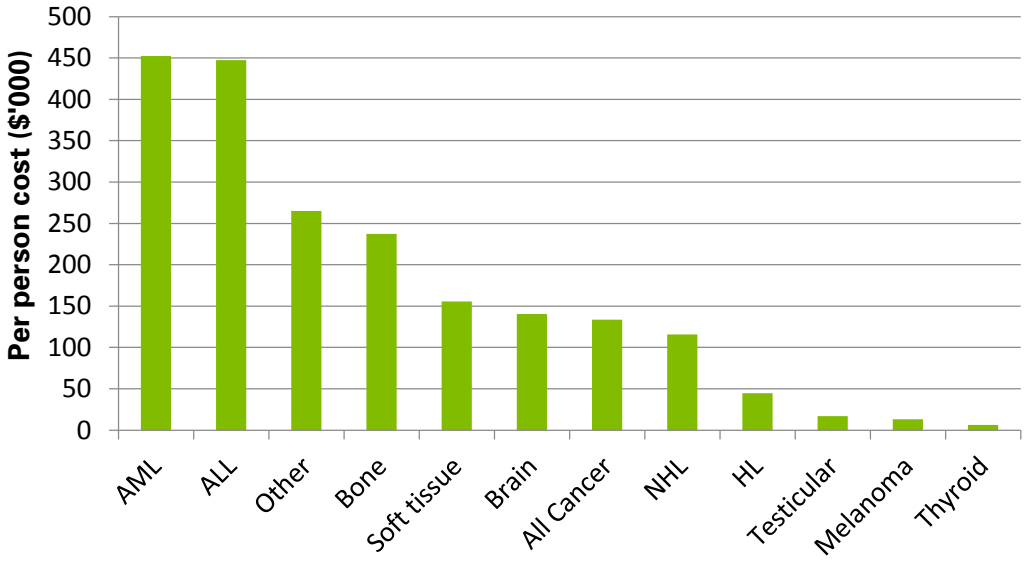
The AIHW estimates include all health system expenditure which is directly attributed to cancer but excludes expenditure on capital goods, non-admitted patient hospital services, over the counter medicines, community health services (except mental health), other health practitioner services, health aids and appliances, patient transport, research[6], health administration and public health programs (other than cancer screening programs) (AIHW, 2013). As only 70% of expenditure data were allocated by the AIHW, all costs were also inflated to allow for non-allocated health costs. All expenditure data were corrected for health inflation since 2008-2009, or since 2001 in the case of melanoma, using data from the AIHW (2005).

This analysis defines health expenditure as those costs which are directly associated with the treatment of cancer, and therefore the costs of screening programs need to be excluded, as they are included in the AIHW estimates.[7] The cost for all cancers included screening programs for breast, bowel and cervical cancer, of which cervical cancer screening was the only screening program relevant to the 15-25 age group in this analysis.[8] Using data on the estimated rate of screening among AYAs, and the expenditure per test, $6.2 million was estimated to have been spent on cervical cancer screening of AYAs in 2008-09 (Medicare Services Advisory Committee, 2013).

The health system expenditure from the AIHW does not include the cost of fertility preservation. The estimated cost of fertility preservation has been separately estimated and added to out-of-hospital expenditure estimates (see Section 5.2.3).

Chart 5.1 and Table 5.1 show the per person lifetime health system expenditure on cancer in 2016, and Table 5.2 shows the estimated total lifetime health system expenditure on cancer for males and females who were diagnosed with cancer in 2016.

Chart 5.1: Estimated per person lifetime health expenditure on cancer



Source: Deloitte Access Economics calculations.

[5] Estimated expenditure for the remaining cancer types was calculated by subtracting the known values from the total, and dividing based on each cancer's share of incident cases.
[6] Note that clinical trials conducted by private organisations are not captured in the analysis.
[7] Note that the costs of awareness/prevention programs (for example, melanoma programs such as SunSmart, Pretty Shady and The Dark Side of Tanning) are not included in the AIHW estimates. The costs of these programs would be classified as government program costs, which are not included in the scope of analysis for this report.
[8] BreastScreen Australia targets asymptomatic women aged 50-69. The National Bowel Cancer Screening Program offers free screening to people turning 50, 55, 60 and 65 years of age. The National Cervical Cancer Screening Program targets women aged 18-69 (AIHW, 2013).

Table 5.1: Estimated lifetime per person health system expenditure

Cancer type	Expenditure ($'000) *People*
Melanoma	13.72
AML	452.79
ALL	447.82
NHL	116.01
HL	45.15
Brain	140.83
Bone	237.76
Softtissue	156.22
Testicular	17.24
Thyroid	7.59
Other	267.59
All Cancer	**134.57**

Source: Deloitte Access Economics calculations.

Table 5.2: Estimated lifetime health system expenditure

Cancer type	Total expenditure ($m)		
	Male	*Female*	*People*
Melanoma	1.1	1.5	**2.7**
AML	11.7	5.3	**17.1**
ALL	12.1	5.6	**17.6**
NHL	4.7	3.4	**8.0**
HL	3.3	3.1	**6.3**
Brain	4.1	3.3	**7.4**
Bone	5.8	3.9	**9.7**
Softtissue	2.8	2.4	**5.2**
Testicular	2.3	0.0	**2.3**
Thyroid	0.2	0.5	**0.7**
Other	30.6	38.8	**69.4**
All Cancer	**78.6**	**67.9**	**146.5**

Source: Deloitte Access Economics calculations.

5.2 HEALTH SYSTEM COSTS BY TYPE OF COST

This section provides further detail on the three types of health system costs which are incurred by AYAs with cancer: prescription pharmaceuticals, in-hospital costs, and out-of-hospital costs. The AIHW (2013) reports on all types of cancer included in this analysis, with the exception of skin cancer and soft tissue cancer.[9] According to the report, the cancers with the highest expenditure as a proportion of all health system costs were ALL (18% of total expenditure) and brain cancer (15% of total expenditure).

5.2.1Prescription pharmaceuticals

Cancer treatment often involves prescription pharmaceuticals including chemotherapy medicines and hormone therapy. Different cancer types and situations require unique treatments which may include a combination of surgery, chemotherapy, hormone therapy and/or radiotherapy (Cancer Council, 2014). Chemotherapy medicines kill or slow the growth of rapidly dividing cells which can include cancer cells but often also normal cells (further information is provided in Section 2.5). Most people have chemotherapy on an outpatient basis; however, some people are able to take chemotherapy at home, while in other cases an overnight stay at a hospital is required (Cancer Council, 2014). In some cases targeted therapies are available, which are more specific in their focus on cancerous cells. Many expensive cancer treatment pharmaceuticals are subsidised by the PBS.

Of the three components of health system costs, prescription pharmaceuticals were the smallest component (1.4%) among AYAs with cancer. Across all cancers, pharmaceuticals accounted for 0.4% of total costs for males and 2.8% of total costs for females (AIHW, 2013). This means that AYAs diagnosed with cancer in 2016 were estimated to incur $2.2 million ($1,700 per person) in pharmaceutical lifetime costs as a result of cancer.

These estimated pharmaceutical costs were sourced from the AIHW (2013), which provided disaggregated estimates of pharmaceutical expenditure for males and females, and for bone cancer, other cancer and all cancers. The report notes that the percentage of all expenditure that is spent on pharmaceuticals is lower than for chronic diseases (12% for cancer compared to 16% for chronic disease).

5.2.2 Admitted patients

Depending on the cancer type and treatment course, people diagnosed with cancer may be admitted to a hospital. Reasons for hospital admission[10] may include surgery, chemotherapy, radiotherapy, other cancer treatments and management of side effects. Expenditure on hospital admitted patients formed the largest proportion of total costs (83.5%) for all cancers among AYAs (AIHW, 2013). The largest costs were for ALL ($15.7 million) followed by AML ($15.2 million). Table 5.3 shows estimated lifetime hospital expenditure on males and female AYAs diagnosed with cancer in 2016.

5.2.3 Out-of-hospital medical services

Out-of-hospital medical services for cancer may include diagnostic services, laboratory services, administering of medication (including patients who are provided same-day chemotherapy), specialists and general practitioner services, and x-ray or pathology tests. They formed 15.1% of the total expenditure among all cancer in AYAs (AIHW, 2013).

Table 5.4 shows the estimated total out-of-hospital expenditure on males and female AYAs diagnosed with cancer in 2016.

[9] The expenditure for all cancer was used for the skin and soft tissue and expenditure calculations.
[10] An admitted patient "undergoes a hospital's admission process to receive treatment and/or care. This treatment and/or care is provided over a period of time and can occur in hospital and/or in the person's home" (AIHW, 2016).

Table 5.3: Estimated lifetime admitted patient expenditure

Cancer type	Total expenditure ($m)		
	Male	*Female*	*People*
Melanoma	0.8	1.1	**1.9**
AML	10.2	4.9	**15.2**
ALL	10.5	5.2	**15.7**
NHL	4.0	3.0	**7.0**
HL	2.7	2.7	**5.4**
Brain	3.5	3.0	**6.6**
Bone	5.0	3.6	**8.6**
Softtissue	2.4	2.2	**4.6**
Testicular	1.9	0.0	**1.9**
Thyroid	0.1	0.3	**0.3**
Other	26.2	35.8	**62.0**
All Cancer	**67.3**	**61.8**	**129.1**

Source: Deloitte Access Economics calculations.
Note: Due to limitations with the underlying data costs have been allocated using the results from Table 5.2, by applying the proportion of admitted patient expenditure (out of total expenditure) for "all cancer" to each cancer type.

Table 5.4: Estimated lifetime out-of-hospital expenditure

Cancer type	Total expenditure ($m)		
	Male	*Female*	*People*
Melanoma	0.3	0.4	**0.7**
AML	1.5	0.2	**1.7**
ALL	1.5	0.3	**1.8**
NHL	0.6	0.2	**0.9**
HL	0.5	0.3	**0.9**
Brain	0.6	0.2	**0.8**
Bone	0.7	0.2	**0.9**
Softtissue	0.4	0.1	**0.5**
Testicular	0.4	0.0	**0.4**
Thyroid	0.1	0.2	**0.3**
Other	4.3	1.9	**6.2**
All Cancer	**11.0**	**4.2**	**15.2**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.
Note: Due to limitations with the underlying data costs have been allocated using the results from Table 5.2, by applying the proportion of out-of-hospital expenditure (out of total expenditure) for "all cancer" to each cancer type, and adding estimated costs for fertility preservation.

FERTILITY PRESERVATION COSTS

Out of hospital costs include costs for fertility preservation. Some cancer treatments including chemotherapy, radiotherapy, bone marrow and surgery may cause temporary or permanent infertility, an issue particularly relevant to AYAs who are less likely to already have children. Fertility preservation is the overarching term used for medical and surgical treatment to minimise the impact of cancer treatment on a patient's future fertility. There are a number of fertility preservation techniques which are standard practice (Levine et al, 2010) and recommended by the 13 international guidance documents of fertility preservation (COSA, 2016). Evidence shows that there are a range of barriers to accessing fertility treatment by AYAs, including a lack of age appropriate information, reluctance to 'have the conversation', and cost (Fardell et al, 2016; Thompson, 2008; Kelvin et al, 2016).

The following are the main methods and costs of fertility preservation in males and females, based on Levine et al (2010) and information from advice from a CanTeen expert group.

Methods and costs of fertility preservation for females include:

- Embryo cryopreservation: a released egg is retrieved and fertilised with sperm from a partner or donor outside the woman's ovary (forming an embryo). The embryo is 'cryopreserved' or frozen for later use. The initial cost of embryo cryopreservation is between $8,000 and $10,000, followed by between $150 and $400 per year for storage.
- Oocyte cryopreservation: similar to embryo cryopreservation however without fertilisation of the egg. This method has a lower success rate but has similar costs to embryo cryopreservation.
- Ovarian cortex cryopreservation: a piece of ovarian tissue is surgically removed and cryopreserved. Costs are generally between $6,000 and $8,000, followed by between $150 and $400 per year for storage.

Methods of fertility preservation for males include:

- Sperm cryopreservation: sperm is cryopreserved for use at a later date. The initial cost of sperm cryopreservation is between $300 and $600, followed by between $150 and $400 per year for storage.
- Testicular sperm extraction: sperm is obtained surgically and cryopreserved. Costs are generally between $1,000 and $3,000, followed by between $150 and $400 per year for storage (Thompson, 2008). Surgical sperm extraction and testicular tissue cryopreservation are used for patients who have neurological or surgical reasons why a sample cannot be collected by masturbation.
- Testicular tissue cryopreservation: pieces of tissue from the testicle are surgically removed and cryopreserved. Costs are generally between $1,000 and $3,000, followed by between $150 and $400 per year for storage/freezing. These procedures are used in pre pubertal male patients who are unable to produce semen.

According to advice from a CanTeen expert group, it can be assumed that 100% of patients will be told about fertility preservation and 75% of patients will have a consultation with a fertility expert. During 2014-15, 36% of patients referred to the YCS underwent fertility preservation (CanTeen, 2016b). Due to more complicated procedures and higher costs, females are less likely to undergo fertility preservation than males (Lambertini et al, 2016). According to advice from a CanTeen expert group the proportion of males who will undergo fertility treatment is 25% larger than the proportion of females. This is approximately in line with the findings by Lambertini et al (2016). Assuming the proportion of newly diagnosed AYAs undergoing fertility preservation in 2016 is the same as in 2014-15 (36%), approximately 392 AYAs from the 2016 cohort will undergo fertility preservation treatment of which 245 (62.5%) are male and 147 (37.5%) female.

The length of storage will depend on both whether fertility recovers following cancer treatment, the risk of relapse following cancer treatment, and the timing of planned parenthood following cancer treatment. Fertility recovery should be assessed following cancer treatment between twelve months and two years after treatment (Van Dorp et al, 2016). Studies show that there may be recovery of fertility for approximately 50% of males (Howell and Shalet, 2005; Osterberg et al, 2014). In female patients the ovarian reserve may be reduced (sub-fertility) but the patient may still be able to give birth naturally. The decline in the ovarian reserve following cancer treatment is less predictable and many females are still at an increased risk of premature ovarian failure (menopause), as the number of oocytes continue to decline with age, so patients may decide to continue storage of frozen embryos even if the cancer treatment has not

resulted in immediate infertility (Thompson, 2008). Additional advice from a CanTeen expert group was that both males and females are reluctant to discontinue storage, regardless of fertility recovery or family prospects. In this analysis it is assumed that all patients who undergo fertility preservation will pay for storage until they are 40.

The cost of fertility preservation was based on the average cost of treatment and storage for males and females as suggested by the CanTeen expert. Using this methodology, it was estimated that the lifetime costs of fertility preservation for the 2016 cohort of AYAs will be $3.5 million.

5.3 WHO BEARS THE COST

According to the AIHW (2015a) report on health expenditure in Australia, 41.2% of total health expenditure is sourced from the Australian Federal Government, 26.6% is from state/territory and local governments, and 17.8% is paid by individuals and their families. The remaining 14.4% of the cost is paid by other parties, such as private health insurers. The breakdown of expenditure by type of cancer is shown in Table 5.5.

Table 5.5: Estimated lifetime expenditure by source

Cancer type	Federal Government ($m)	State/ territory ($m)	Individuals ($m)	Other parties ($m)	Total ($m)
Melanoma	1.1	0.7	0.5	0.4	**2.7**
AML	7.0	4.5	3.0	2.5	**17.1**
ALL	7.3	4.7	3.1	2.5	**17.6**
NHL	3.3	2.1	1.4	1.2	**8.0**
HL	2.6	1.7	1.1	0.9	**6.3**
Brain	3.1	2.0	1.3	1.1	**7.4**
Bone	4.0	2.6	1.7	1.4	**9.7**
Soft tissue	2.1	1.4	0.9	0.7	**5.2**
Testicular	0.9	0.6	0.4	0.3	**2.3**
Thyroid	0.3	0.2	0.1	0.1	**0.7**
Other	28.6	18.5	12.4	10.0	**69.4**
All Cancer	**60.3**	**39.0**	**26.1**	**21.1**	**146.5**

Source: Deloitte Access Economics calculations.

6. Productivity costs of cancer

This chapter describes the approach that was used to estimate productivity costs associated with cancer in AYAs in Australia.

Key findings

For AYAs diagnosed in 2016, the total lifetime productivity cost was estimated as $508.4 million.

The cost of temporary absenteeism was estimated to be $2.8 million. The long term cost due to lower employment was $290.1 million, and the lost productivity due to premature death was $162.0 million.

In total, the productivity costs of cancer in AYAs excluding informal care were $455.7 million. In addition to these costs, the cost of informal care was $52.7 million.

6.1 APPROACH

Being diagnosed with cancer can affect individuals' productivity or capacity to work, both in the long and short term. If employment rates are lower for people with cancer, this loss in productivity represents a real cost to the economy. Additionally, informal carers may also work less or not work entirely in order to care for their loved one with cancer, and this represents an additional productivity loss. Initially, being diagnosed with cancer may result in reduced hours, restricted activities, changed responsibilities or occupations. Health concerns and treatment associated with cancer may cause people to be temporarily absent from paid employment more often than the general population. Furthermore, cancer treatment may result in lower employment rates in the years following. These factors also lead to productivity-related administrative costs, which are covered in Section 6.5.

This report measured the lost earnings and production due to cancer diagnosis using a 'human capital' approach. The lower end of such estimates includes only the 'friction' period until the worker can be replaced, which would be highly dependent on labour market conditions and unemployment/underemployment levels. In an economy operating at near full capacity as Australia is, a better estimate includes costs of temporary work absences plus the discounted stream of earnings after diagnosis lost due to early retirement from the workforce, reduced working hours (for example, part-time rather than full time) and premature mortality. These approaches are outlined in Section 6.2 to Section 6.5.

In calculating productivity costs, it is important to note that the proportion of AYAs in full- or part-time education is higher than the rest of the population. This rate of participation in education is a key driver for employment rates among AYAs being lower than employment rates among the rest of the working age population (ABS, 2016a). The lower employment rates mean that short-term productivity losses among AYAs will be less than for other ages, as fewer AYAs would be in employment even in the absence of cancer. However, long-term productivity losses due to disrupted education are partly captured in reduced employment over the life of an AYA.

In addition to the lost productive capacity of the AYA with cancer, there is also a cost imposed on their informal carers. These costs are covered in Section 6.6.

6.2 Absenteeism

Short term productivity losses from temporary absenteeism are defined as the number of days per year an employee is unable to work due to cancer. No Australian specific estimates were available for temporary absenteeism from work and therefore academic literature was searched to identify any AYA-specific parameters.[11]

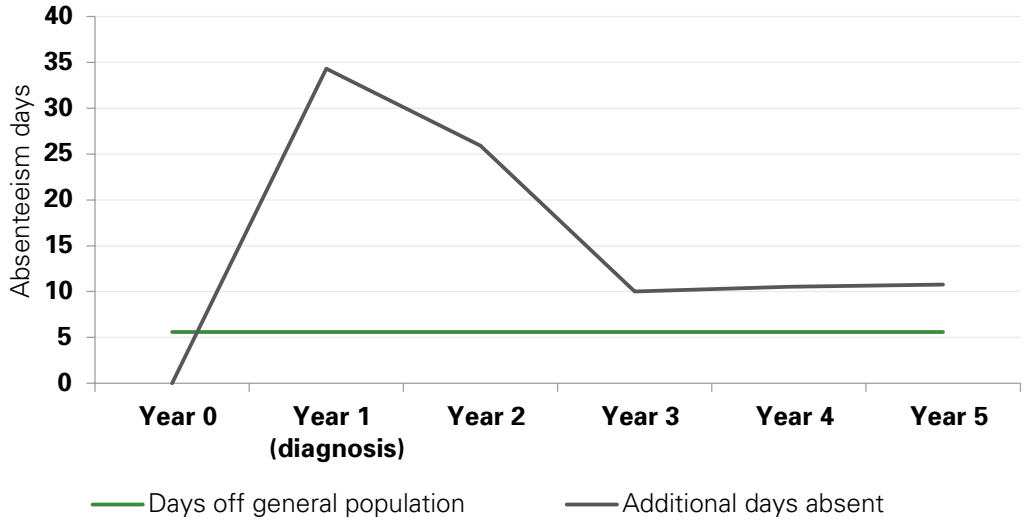
The overall five-year impact on AYAs with cancer was sourced from Dowling et al (2010), who reported the mean work loss days for childhood cancer survivors[12] in the United States of America (USA) 0-4 years since diagnosis was 23.9 days per year on average over the five year period. For those aged 18-29 years in the survey without cancer (i.e. the comparison

population), the mean work loss days in the 12 months preceding the survey was 5.6 days. Thus, on average, AYAs with cancer who work have an additional 18.3 days away from work per year in the 5 years following diagnosis.

To break down the absenteeism estimate into each year over the five year period, sick leave patterns from a study in Norway (Torp et al, 2012) were applied to the estimates provided by Dowling et al (2010). Torp et al (2012) found that there was a substantial increase in those taking sick leave within the first year following diagnosis. For the population with cancer, the ratio of sick leave in the first year relative to the average sick leave taken by this population over the five years was approximately 1.7 times greater. The proportion taking sick leave in the second and third years decreases at approximately a linear rate until sick leave patterns are more similar to the population without cancer, albeit still higher. The ratio of sick leave taken by the population with cancer in years two to five relative to the average sick leave taken by this population over the five years was approximately 0.7 times the average.

Chart 6.1 presents the mean loss in work days in each year following diagnosis for AYAs with cancer who work, after the sick leave pattern from Torp et al (2012) were applied to the absenteeism estimates reported by Dowling et al (2010).

Chart 6.1: Estimated temporary absenteeism in the years following diagnosis



Source: Deloitte Access Economics calculations based on Dowling et al (2010), and Torp et al (2012).
Days absent relates to AYAs with cancer who work, where Year 1 is 2016.

The underlying data from Chart 6.1 is shown in Table 6.1.

Table 6.1: Estimated temporary absenteeism in the years following diagnosis

Days off work	Year 1	Year 2	Year 3	Year 4	Year 5
Population with cancer	39.9	31.5	15.6	16.1	16.4
General population	5.6	5.6	5.6	5.6	5.6
Additional days	**34.3**	**25.9**	**10.0**	**10.5**	**10.8**

Source: Deloitte Access Economics calculations based on Dowling et al (2010), and Torp et al (2012).
Days off work relates to AYAs with cancer who work, where Year 1 is 2016.

[11] Estimates from the Australian Health Survey and the Survey of Disability, Ageing and Carers could not be used due to small sample sizes in these surveys.
[12] Participants in the study were diagnosed with cancer before 20 years of age.

The present value in 2016 dollars of temporary absenteeism due to AYAs being diagnosed with cancer in 2016 was estimated to be $2.75 million of which $0.23 million is incurred by the employee (additional days of paid sick leave) and $2.52 million is incurred by the employer.

As absenteeism is a measure of reduced productivity among the employed population, the estimated cost of temporary absenteeism factors in a drop in employment rates, as outlined in Section 6.3. This is different for each type of cancer, with aggregate results shown in Table 6.2.

6.3 Workforce participation

Avenues through which cancer can lead to long-term reductions in the productive capacity of the labour force include long-term absence from employment. The following results from data and literature sources were used to estimate the long term change in employment for AYAs with cancer.

While significant research has been done on employment and quality of life after cancer diagnosis, few focused specifically on those diagnosed with cancer as AYAs. A study by Langeveld et al (2003) was the only literature identified which contained AYA-specific employment rates. As no AYA-specific return to work patterns could be located, results from Short et al (2005) were applied to the long term outcomes expected for AYAs. Finally, results from Syse et al (2008) were used to disaggregate the effects into different types of cancers.

Short et al (2005) examined employment pathways of cancer survivors five years after diagnosis in the US. This study included 1,433 cancer survivors who were interviewed one to nearly five years after diagnosis about their employment pathways. It found that of 88% of male survivors and 78% of female survivors who were working at the time of diagnosis, 41% and 39% stopped working during cancer treatment (0-5 months after diagnosis). Cancer survivors gradually returned to work, however at 36-47 months after diagnosis, only 84% of cancer survivors had returned to work (Short et al, 2005).

Langeveld et al (2003) conducted a study on the long term effects of childhood cancer in 500 childhood cancer survivors in the Netherlands compared to a control group, and found that the percentage of employed male and female survivors of childhood cancers was 25% and 18% lower compared to the control group (53% versus 78% in males, and 53% versus 71% in females). Male childhood cancer survivors were also significantly less likely to be employed on a full time basis (85% versus 92%). The age range in this study of both the survivors (median age 26, range 15-53) and the comparison group (median age 22, range 16-49) went beyond that of this analysis on AYAs. However, the authors found that differences in results were not statistically significant between different age groups.

Syse et al (2008) explored the impact of cancer on employment for 34,000 cancer survivors in Norway using register data covering the entire Norwegian population in 2001. Survivors were between 40-59 years old in 2001. The study used logistic regression models to estimate the odds ratios of employment for cancer survivors relative to people with no history of cancer, stratified by cancer type, stage and gender. The authors found that cancers such as brain cancer, lung cancer and leukaemia have a greater impact on chance of employment than cancers such as skin or testicular cancer.

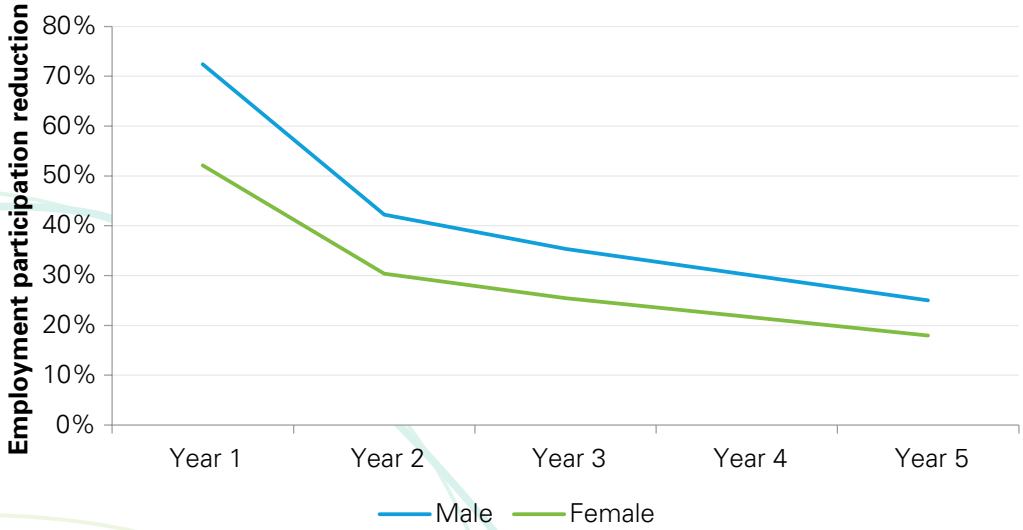
Combining the results from the three studies, the estimated annual reduction in employment by males and females across all cancer types is shown in Table 6.2 and Chart 6.3. Note that different reductions were calculated for each cancer type.

Table 6.2: Estimated percentage reduction in employment participation

	Year 1	Year 2	Year 3	Year 4	Year 5
Male	-72.4%	-42.2%	-35.3%	-30.2%	-25.0%
Female	-52.1%	-30.4%	-25.4%	-21.7%	-18.0%

Source: Based on Langeveld et al (2003), Short et al (2005) and Deloitte Access Economics calculations.
Participation reductions relate to AYAs with cancer, where Year 1 is 2016.

Chart 6.2: Estimated percentage reduction in employment participation



Source: Based on Langeveld et al (2003), Short et al (2005) and Deloitte Access Economics calculations.
Participation reductions relate to AYAs with cancer, where Year 1 is 2016.

It was estimated that the first year impact across all cancers was 72% in males and 52% in females, for AYAs. By the fifth year, this had decreased to 25% for males and 18% for females, and these reductions were assumed to continue over the remaining life of each AYA cancer survivor.

These results were triangulated with the results of a meta-analysis conducted by De Boer et al (2006). This study undertook a long-term follow up (average 15 years) of unemployment among childhood cancer survivors for a specific subset of cancers, and found that across all cancer types the odds ratio of unemployment was 1.85. Applying this to current unemployment among Australians aged 15-24 (12.2%) gives an estimated reduction in employment of 22.6%[13], which is equivalent to the average across male (25%) and female (18%) AYAs (ABS, 2016a). While increased unemployment is not a perfect reflection of decreased employment,[14] it serves as a useful triangulation in the absence of alternative sources of data.

Employment outcomes can vary widely depending on the cancer type. For example, for AYAs with brain cancer, employment outcomes would be expected to be substantially worse than for those with melanomas. For all cancers in AYAs, the long term productivity cost due to decreased employment was $290.1 million. This is the NPV of lifetime costs (see Section 3.3), which go beyond 5 years after cancer diagnosis. Table 6.3 shows a breakdown of these costs by cancer type.

[13] Calculated as 1.85 * 12.2%
[14] Unemployment occurs when a person who is actively seeking work is unable to find work. A decrease in employment could occur without a corresponding increase in unemployment, if people are not actively seeking work.

Table 6.3: Estimated lifetime cost of reduced workforce participation, AYAs with cancer

Cancer type	Male($m)	Female ($m)	People ($m)
Melanoma	23.7	13.6	**37.3**
AML	7.9	2.5	**10.3**
ALL	11.1	1.6	**12.7**
NHL	17.4	5.3	**22.7**
HL	24.9	12.1	**37.0**
Brain	19.9	8.1	**28.0**
Bone	11.9	4.5	**16.4**
Soft tissue	6.0	2.4	**8.4**
Testicular	43.3	0.0	**43.3**
Thyroid	7.3	12.2	**19.5**
Other	39.3	15.2	**54.5**
All Cancer	**212.7**	**77.4**	**290.1**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

6.3.1 Educational impacts

Cancer is likely to have a disruptive impact on education for AYAs who are diagnosed while in school or further education. These disruptions could include missing periods of secondary or tertiary education as a result of cancer treatment, and also cancer negatively impacting on the level of focus which can be directed to studying.

Langeveld (2003) examined the impact of cancer on education and employment and found that in the long term, survivors of childhood cancer[15] are 19% less likely to have a high school or tertiary qualification. The impact of cancer on educational achievement in the Langeveld (2003) study was strongest in brain cancer. For young adults who had had childhood brain cancer, 80% did not complete high school compared to 57% of the population. Langeveld (2003) also found a positive relationship between cranial irradiation as part of the cancer treatment for leukaemia and NHL and lower education in later years. In addition to the long term impacts on education, AYAs are likely to lose short term days from their education due to cancer.

While the specific calculation of education costs is beyond the scope of analysis for this report, the quantitative impact of this on productivity is partly captured in the workforce participation impacts, as reduced levels of education are reflected in labour market participation.[16] Disrupted education can also result in cancer survivors working in lower paid jobs, or making positive changes to their career direction as a result of their experience. In addition to these impacts on productivity, there are also costs imposed such as for additional lesson planning, one to one class support, private tutors or repeating periods of education. Quantification of these costs was beyond the scope of analysis for this report.

6.4 PREMATURE MORTALITY

To calculate productivity costs due to premature mortality, the mortality rate for cancer and the expected remaining lifetime earnings of people with cancer (weighted against the probability of being employed by age and gender) were used. For all cancers, the estimated lifetime costs were $162.0 million in productivity costs due to premature death. Table 6.4 shows a breakdown of these costs disaggregated by gender and cancer type.

[15] Participants in the study were diagnosed with cancer before the age of 19.
[16] Access Economics (2007) estimated that disrupted education due to childhood cancer permanently reduced lifetime earnings by 9.6%. A fuller discussion on the impact of childhood cancer on education is provided in this report.

Table 6.4: Estimated lifetime costs from premature mortality

Cancer type	Male ($m)	Female ($m)	People ($m)
Melanoma	5.0	4.4	**9.4**
AML	11.5	6.2	**17.8**
ALL	14.0	3.6	**17.6**
NHL	9.8	4.1	**13.8**
HL	3.4	2.3	**5.7**
Brain	15.4	6.7	**22.1**
Bone	13.8	3.6	**17.5**
Softtissue	6.0	3.3	**9.2**
Testicular	5.2	0.0	**5.2**
Thyroid	0.4	0.2	**0.6**
Other	24.7	18.5	**43.1**
All Cancer	**109.1**	**52.9**	**162.0**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

6.5 PRODUCTIVITY-RELATED ADMINISTRATION COSTS

The employer also incurs productivity-related administrative costs associated with short run and long run productivity costs. Each day a person with cancer is temporarily absent from work, it was estimated that 2.5 hours of management time is lost processing those absent employees (Health and Safety Executive, 2011). This includes the time of line managers in rearranging work and the time of back office personnel. After correcting for inflation, the value of a manager's time was estimated to be $45.70 per hour in 2016 (ABS, 2014).

Premature retirement and premature mortality results in increased employee turnover costs, such as search, hiring and training costs. These costs were estimated to be equal to 26 weeks' salary of the incumbent worker (Access Economics, 2004). However this cost is 'brought forward' a number of years because there would be some normal turnover of people – approximately 15% per annum (which implies that people change jobs, on average, approximately once every 6.7 years (Access Economics, 2004).

Productivity-related administration costs for all cancers diagnosed in AYAs in 2016 were estimated to be $0.8 million in lifetime costs.

6.6 INFORMAL CARER PRODUCTIVITY LOSSES

Carers are people who provide informal care to others in need of assistance or support. For example, carers may take time off work to accompany AYAs with cancer to medical appointments, stay with them in hospital, or care for them at home. Informal care is distinguished from services provided by people employed in the health and community sectors (formal care) because the care is generally provided free of charge to the recipient and is not regulated by the government. Most informal carers are family or friends of the person receiving care. While informal care is provided free of charge, it is not free in an economic sense, as time spent caring is time that cannot be directed to other activities such as paid work, unpaid work (such as housework or yard work) or leisure. As such, informal care is a use of economic resources.

There are three potential methodologies which can be used to place a dollar value on the level of informal care:

- the opportunity cost method – measures the formal sector productivity losses associated with caring, as time devoted to caring responsibilities is time which cannot be spent in the paid workforce;
- the self-valuation method – measures how much carers feel they should be paid for undertaking their responsibilities; and
- the replacement cost method – measures the cost of "buying" an equivalent amount of care from the formal sector, if the informal care were not supplied.

The self-valuation method is not commonly used, and there are no reliable Australian studies of the amount Australian carers feel they should be compensated. In this study, the replacement cost method was used, due to an absence of data that would be needed to use the opportunity cost method. Note that some people with cancer and their carers may actually increase their productivity (at the expense of their leisure time) in order to pay for their increased cancer-related expenses or as a distraction from the illness. However, due to a lack of data, this effect has not been able to be estimated in this analysis.

The typical approach to estimating the cost of informal care is to use data extracted from the Survey of Disability, Ageing and Carers (SDAC). However, due to a very small number of AYAs with cancer being surveyed in the SDAC, additional sources from literature were used to estimate the hours spent by carers and the demographic profile of carers who provide informal care to AYAs with cancer. A large study from the USA was considered to provide a reasonable approximation of informal carer time in Australia, for AYAs with active cases of cancer.

Yabroff and Kim (2009) used data from a large national study of cancer patient caregivers in the USA to estimate the time costs associated with informal caregiving for cancer survivors. Cancer survivors who participated had to be at least 18 years old and been diagnosed with at least 1 of the 10 most common cancers, including bladder, breast, colorectal, kidney, lung, melanoma of the skin, ovarian, prostate, uterine and NHL.

Participants were asked to nominate one individual who consistently provided help, including emotional support, financial support, symptom management, personal care, or transportation support during their cancer experience. It was found that for patients younger than 24, caregivers had spent a mean total of 2,661 hours providing care in the last two years, equating to approximately 25.5 hours per week.

The results from Yabroff and Kim (2009) were compared with the results from Cohn et al (2003). This study interviewed 100 parents in Australia around 3.4 years post-diagnosis, on average, and asked them to estimate the financial impact on the family as a result of informal care provided to a child with cancer. The study found that 28% of families experienced a loss of income through reduced paid hours (including resigning from employment) at an average cost of $2,505 in income per year per child diagnosed with cancer. Using average rates of pay, this is equivalent to approximately 6 hours per week. While this result appears to be significantly lower than the estimate from Yabroff and Kim (2009), it is important to note that most cancer cases included in the Cohn et al study would no longer be active, as the average time post diagnosis was 3.4 years. Thus, the average amount of time consisted of both active and non-active cases.

The hours spent caring for AYAs per week used for this analysis was 25.5, in accordance with the Yabroff and Kim (2009) estimate of hours of carer time for cancer patients older than 18 and younger than 24. This value is care given specifically as a result of cancer, i.e. it is additional to any care which may be provided normally. For the replacement value of carer time per hour, the value calculated in the 2015 Deloitte Access Economics report for Carers Australia on the economic value of informal care in Australia ($31.36) was inflated to 2016 using the wage price index over 2015-16 (2.1%; ABS, 2016b) resulting in $32.02 per hour. For all cancers in 2016, it was estimated that the cost of informal care for AYAs was $52.7 million. This is comprised of:

- losses to carers in the form of lost income: $33.8 million; and
- losses to government in the form of lost taxes: $18.9 million.

Table 6.5 shows the cost of informal care for AYAs disaggregated into different cancer types.

Table 6.5: Estimated lifetime cost of informal care

Cancer type	Male ($m)	Female ($m)	People ($m)
Melanoma	3.7	5.0	**8.7**
AML	1.1	1.0	**2.0**
ALL	1.7	0.7	**2.5**
NHL	1.9	1.3	**3.2**
HL	3.2	3.2	**6.4**
Brain	1.8	1.4	**3.2**
Bone	1.8	0.8	**2.5**
Softtissue	1.0	0.9	**2.0**
Testicular	5.9	0.0	**5.9**
Thyroid	0.8	3.0	**3.8**
Other	5.3	7.1	**12.4**
All Cancer	**28.2**	**24.5**	**52.7**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding. Due to a lack of data which are specific to each cancer type, costs in this table are apportioned based on incidence of each cancer.

6.7 SUMMARY OF PRODUCTIVITY COSTS

For AYAs diagnosed in 2016, it was estimated that the total lifetime productivity costs for all cancers is $508.4 million. Table 6.6 shows a summary of the total lifetime productivity costs for all cancers in AYAs.

Table 6.6: Summary of lifetime productivity costs

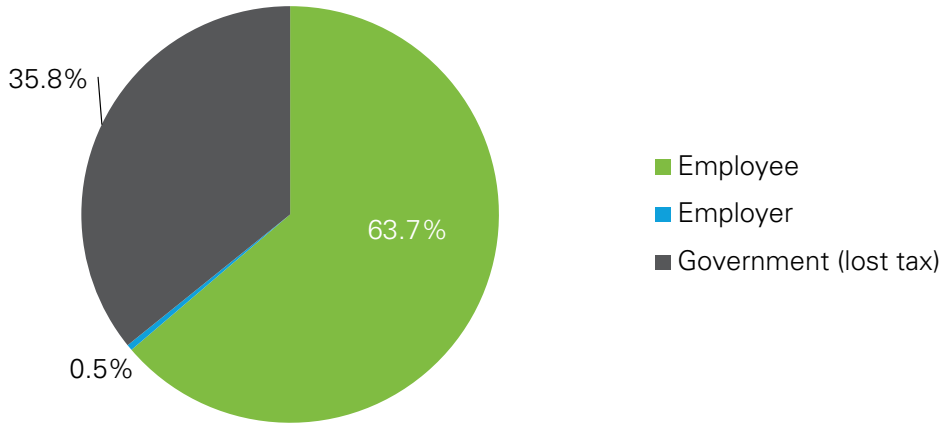
Source of productivity loss	Cost ($m)
Absenteeism	2.8
Lower workforce participation	290.1
Premature mortality	162.0
Informal carer costs	52.7
Productivity - related administrative costs	0.8
Total	**508.4**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding. Due to a lack of data which are specific to each cancer type, costs in this table are apportioned based on incidence of each cancer.

For all cancers, the majority of productivity costs resulted from decreased workforce participation (57% of total cost) and premature mortality (32%). Carer costs formed 10% of the total cost, and absenteeism and productivity-related administrative (turnover) costs formed the final 1%.

Chart 6.3 shows that for cancer productivity costs (including absenteeism, lower workforce participation, premature mortality and productivity-related administrative costs), approximately 63.7% was incurred by the employees in reduced income, 0.5% by employers (as extra sick leave taken), and 35.8% by the government in the form of lost taxes.

Chart 6.3: Distribution of productivity costs



Source: Deloitte Access Economics calculations.

7. Transfers

Transfer payments represent a shift of resources from one economic entity to another, such as raising taxes from the entire population to provide welfare payments to people with cancer. The act of taxation and redistribution creates distortions and inefficiencies in the economy, so transfers also involve real net costs to the economy, known as DWLs.

Transfer costs are important when adopting a whole-of-government approach to policy formulation and budgeting. Transfer costs also allow us to examine the distribution of the costs of cancer across different parts of society. This chapter calculates the transfer costs resulting from income support, government health expenditure, and lost taxes, and calculates the resultant DWL from these transfers.

Key findings

Over their lifetime, cancer among the approximately 1,100 AYAs diagnosed with cancer in 2016 results in $182.0 million in lost taxes, $99.3 million in health system costs borne by the government, and $21.4 million in welfare payments, for a total of $302.0 million in transfers, in 2016 dollars. The resultant DWL (calculated as a proportion of the total transfer costs) is $87.8 million in lifetime costs.

7.1 INCOME SUPPORT FOR AYAS WITH CANCER

There are four main sources of income support for people with cancer. The Disability Support Pension (DSP), Sickness Allowance (SKA), NewStart Allowance (NSA), and Youth Allowance (YLO). These are explored in the following sections. A special data request was submitted to the Department of Social Services (DSS) to obtain data on the number of AYAs with cancer and their carers accessing income support, and the value of payments made to them.

7.1.1 Disability Support Pension (DSP)

The main source of income support for AYAs with cancer is the DSP, which is payable to people aged less than 65 years. DSP is an income support payment for people who are unable to work for 15 hours or more per week at or above the relevant minimum wage, independent of a Program of Support, due to permanent physical, intellectual or psychiatric impairment. A DSP claimant must be aged 16 years or over and under Age Pension age at date of claim, however once in receipt of DSP, a person can continue to receive DSP beyond Age Pension age.

According to the most recent DSS annual report, as of June 2015, there were 814,391 people in Australia who were listed to have received the DSP, at a total cost of $16.54 billion over 2014-15, or $20,310 per person (DSS, 2015). This amount was adjusted to 2016 using the Consumer Price Index, which results in a per person cost of $20,442. A special data request from the DSS showed that there were 452 AYA recipients of a DSP with cancer in 2015, which is 36% of the 2016 AYA active prevalence.17 Assuming that 36% of the 1,088 cases diagnosed in 2016 will receive the DSP, and that this ratio will hold over the future years for active cases, the lifetime costs of the DSP for the 2016 cohort will be $10.6 million.

However, some of these AYAs would have received DSP payments even in the absence of cancer, which must be netted out to estimate the additional welfare payments due to cancer. A University of Melbourne study (Tseng and Wilkins, 2002) estimates that the 'reliance' of the general population (aged 15-64 years) on income support is 10.2% for males and 14.9% for females. These results were weighted by the number of males and females with cancer who accessed the DSP in 2015, and resulted in an average for all cancers of 12.4%. This varied from a high of 14.0% for thyroid cancer, to a low of 10.2% for testicular cancer, depending on the gender distribution of each cancer type. The weighted reliance on the DSP (in the absence of cancer) was subtracted from the DSP payments to get the additional value of the DSP which will be paid to AYAs as a result of their cancer.

Thus, approximately $9.3 million in additional DSP payments will be paid to AYAs diagnosed with cancer in 2016. Table 7.1 shows additional DSP payments to AYAs diagnosed with cancer in 2016 disaggregated into different cancer categories.

Three primary assumptions were made in calculating the value of DSP payments made to the 2016 cohort over their lifetimes.

- There were more medical conditions for which a DSP was received (540) than recipients of a DSP with cancer (425), meaning that some individuals had multiple cancers. In correcting for this, proportionally more values were removed from conditions for which more welfare payments were received.
- Supressed values less than 20 were assumed to be 10.
- There were more people with brain cancer who received a DSP in 2015 than the modelled active prevalence of brain cancer. This likely represents the long-term impact of brain cancer on health outcomes. To correct for this, it was assumed that all of the active prevalent population with brain cancer receive the DSP.

Table 7.1: Estimated net lifetime DSP expenditure

Cancer type	DSP recipients	DSP expenditure ($m)
Melanoma	10	0.07
AML	17	0.33
ALL	18	0.34
NHL	11	0.22
HL	23	0.44
Brain	171	1.37
Bone	10	0.18
Softtissue	6	0.10
Testicular	10	0.07
Thyroid	10	0.18
Other	165	6.00
All Cancer	**452**	**9.29**

Source: Special data request from DSS and Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding. Data were provided for HL, NHL, brain, other cancer, and total. The remaining cancers were calculated by subtracting the known values from the total and apportioning based on incidence.

7.1.2 Sickness Allowance (SKA)

SKA is a payment available to people 22 years and over who are temporarily unfit, due to illness or injury, to perform their usual work or study, and have a job to return to or intend to resume studying when fit to do so. Data include recipients who are determined to be current (that is, entitled to be paid) on the Centrelink payment system and not in receipt of a zero rate of payment. The assumed fortnightly payment for people with cancer receiving the SKA was $527.60, which is the rate of SKA published by the Department of Human Services (DHS, 2016a) for those aged 22 and older with no children.

[17] Recipients in 2015 will include those who were diagnosed in 2015, as well as those who were diagnosed in previous years and are still considered to be active.

A small number of AYAs with cancer (28 in total) received the SKA as at December 2015. Reliance on the SKA that would exist in the absence of cancer was netted out using the Tseng and Wilkins methodology discussed above, and the weighted average of reliance on the SKA by the AYA population with all cancer was 2.8%.

Thus, approximately $0.4 million in additional lifetime SKA payments will be paid to AYAs older than 22 diagnosed with cancer in 2016. Table 7.2 shows additional SKA payments to AYAs diagnosed with cancer in 2016 disaggregated into different cancer categories. The number of recipients of the SKA was suppressed by the DSS for all cancer categories as the values were less than 20. It was assumed that the ratio of SKA would be comparable to the ratio for the DSP and the total of 28 people receiving the SKA was divided over the cancer categories accordingly. Table 7.2 shows additional SKA payments to AYAs diagnosed with cancer in 2016 disaggregated into different cancer categories.

Table 7.2: Estimated net lifetime SKA expenditure

Cancer type	SKA recipients	SKA expenditure ($m)
Melanoma	1	0.01
AML	1	0.01
ALL	1	0.01
NHL	1	0.01
HL	1	0.02
Brain	11	0.14
Bone	1	0.01
Softtissue	0	0.00
Testicular	1	0.01
Thyroid	1	0.01
Other	10	0.19
All Cancer	**28**	**0.43**

Source: Special data request from DSS and Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding. Data were not provided at the individual cancer level.
The total value of SKA payments was apportioned based on the share of DSP payments for each type of cancer as per Table 7.1.

7.1.3 NewStart Allowance (NSA)

The NSA is a payment made to people who are aged 22 years or older and who are looking for paid work. The assumed fortnightly payment for people with cancer receiving the NSA was $527.60, which is the rate of NSA published by the DHS (2016b) for those who are single with no children.

A special data request from the DSS showed that there were 188 AYA recipients of the NSA with cancer in 2015. The reliance on NSA that would exist in the absence of cancer was netted out using the Tseng and Wilkins methodology discussed above, which resulted in the weighted average of reliance on the NSA by the AYA population across all cancers being 12.2%.

A net of $2.6 million in additional NSA payments will be paid to AYAs older than 22 diagnosed with cancer over their lifetime. Table 7.3 shows the NSA expenditure disaggregated into different cancer types. The data for leukaemia, bone, skin, testicular and thyroid cancer were suppressed as there were less than 20 people receiving an NSA with these conditions. For this reason counts for those cancer categories are approximations.

Table 7.3: Estimated net lifetime NSA expenditure

Cancer type	NSA counts	NSA expenditure ($m)
Melanoma	10	0.12
AML	5	0.06
ALL	5	0.06
NHL	8	0.10
HL	17	0.22
Brain	46	0.55
Bone	10	0.12
Soft tissue	2	0.03
Testicular	10	0.12
Thyroid	10	0.12
Other	64	1.09
All Cancer	**188**	**2.60**

Source: Special data request from DSS and Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

7.1.4 Youth Allowance (YLO)

The YLO is a payment made to people who are 16-21 years of age, are looking for full time work, or are undertaking other approved activities. It is also given to 18-24 year olds who are studying full time and 16-24 year olds who are undertaking an apprenticeship.

The maximum fortnightly YLO rate for people under 18 who are single with no children and living at home is $237.10. For people who are over 18, single with no children living at home, the rate is $285.20. For people over 18 who are single and living away from home, the rate is $433.20 (DHS, 2016c). For this analysis the assumption was made that everyone in the 16-19 age group lives at home, while 51% of the 20-24 year olds live at home and 49% live away from home (ABS, 2015a).

A special data request from the DSS showed that there were 124 AYA recipients of the YLO with cancer in 2015. The reliance on YLO that would exist in the absence of cancer was netted out using the Tseng and Wilkins methodology discussed above. This resulted in a net of $1.0 million in additional YLO payments being paid to AYAs diagnosed with cancer in 2016 over their lifetime.

Table 7.4 shows the net YLO expenditure disaggregated into different cancer types. Due to low numbers, the data were suppressed for all cancers except brain cancer, other cancers, and the total for all cancers. For this reason YLO recipient counts were approximations for all other cancer categories, based on their share of incident cases in 2016.

Table 7.4: Estimated net lifetime YLO expenditure

Cancer type	YLO recipients	YLO expenditure ($m)
Melanoma	10	0.06
AML	5	0.03
ALL	5	0.03
NHL	3	0.02
HL	7	0.05
Brain	26	0.16
Bone	10	0.06
Softtissue	2	0.01
Testicular	10	0.06
Thyroid	10	0.06
Other	36	0.43
All Cancer	**124**	**1.00**

Source: Special data request from DSS and Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

7.2 INCOME SUPPORT FOR CARERS OF AYAS WITH CANCER

There are two main income support measures available to primary carers:

- Carer Payment is a means-tested income support payment payable to people who cannot work full time because they provide home-based care to an adult or child who has a severe and long-term disability or health condition, or the equivalent amount of care to a number of less disabled people.[18]
- Carer Allowance is a non-means tested income supplement for people who provide daily care to an adult or child with a severe and long-term disability or health condition.

Information on income support for carers of AYA with cancer was specially requested from the DSS, and can be found in Table 7.5. Data were based on recipients caring for a person with cancer as the primary medical condition. Note that any value under 20 was supressed to maintain anonymity, and for this reason the carer payment and carer allowance for skin cancer, thyroid cancer and testicular cancer, and the carer payment for bone cancer, are estimates. Additionally, some care receivers noted more than one medical condition (i.e. there were less carer payments than medical conditions for which payment was received) which was corrected for.

Table 7.5: Estimated Carer Payments and Carer Allowances for carers

Cancer type	Carer Payment recipients	Carer Allowance recipients	Carer Payment value ($'000)	Carer Allowance value ($'000)	Total ($'000)
Melanoma	5	2	14.8	0.9	**15.8**
AML	23	44	374.5	139.7	**514.3**
ALL	24	45	390.4	145.7	**536.1**
NHL	7	13	107.3	43.3	**150.5**
HL	13	27	25.7	10.4	**36.1**
Brain	44	125	42.7	23.9	**66.6**
Bone	5	23	78.1	73.5	**151.6**
Softtissue	2	15	29.5	48.1	**77.7**
Testicular	5	2	78.1	5.0	**83.1**
Thyroid	5	2	78.1	5.0	**83.1**
Other	144	496	3,934.8	2,426.1	**6,360.9**
All Cancer	**276**	**793**	**5,154.2**	**2,921.6**	**8,075.8**

Source: Special data request from DSS and Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding. Data were provided for AML, ALL, brain, NHL, HL, other cancer and total for the Carer Payment; and for AML, ALL, bone, brain, HL, NHL, other cancer and total for the Carer Allowance.
The remaining cancer types were estimated by deducting the known amounts from the total and dividing based on incidence.

The average entitlement for the Carer Payment was $626.00 per fortnight, and the Carer Allowance was $123.50 per fortnight. In total, for AYAs with all cancers diagnosed in 2016 an estimated 279 carer payments and 793 carer allowances will be received, resulting in a lifetime value of $5.2 million in carer payments and $2.9 million in carer allowances.

7.3 TAXATION REVENUE

People with cancer and their carers in paid employment, who have left the workforce temporarily due to caring responsibilities, or permanently due to premature retirement or death, will contribute less tax revenue to the government.

Consistent with Deloitte Access Economics' standard methodology, in terms of allocating these losses to either personal income or company income, only the employer losses were included as lost company revenue, with the remainder allocated as lost personal income in one form or another. The average personal income tax rate is 22.8% and the average indirect tax rate is 13.0%, based on the Deloitte Access Economics Macroeconomic model. Furthermore the vast majority of company income is distributed to domestic shareholders (as franked dividends) and thus the income is charged at the relevant personal tax rate.

Lost tax revenue represents a lifetime decrease in tax revenue due to lower productivity for AYAs with cancer and their carers, as is discussed in Chapter 6. Lower productivity is reflected in reduced income (as employees are assumed to be paid an income that is equivalent to the value of their output), and will therefore reduce taxes. The total lost tax revenue for all cancers due to AYAs with cancer was $182.0 million, of which $125.9 million was for male and $56.1 million was for female AYAs with cancer.[19] This represents taxation lost that must be collected from remaining citizens (given no change in expenditure – that is, small tax changes are unlikely to change the level of demand for expenditure).

[18] The person with cancer must also be in receipt of an income support payment.
[19] This difference between males and females reflects the higher employment rate among males, higher male incomes, and the larger reduction in male employment compared to female employment (see Table 6.2).

7.4 TRANSFER COSTS SUMMARY

Table 7.6 shows the components of transfer costs for all cancers in AYAs. Cancer in AYAs diagnosed in 2016 leads to $302.0 million in lifetime transfer costs. Note that these are not a net cost to society (see Section 7.5).

Table 7.6: Components of transfer costs

Transfer costs	$m
Health system costs borne by government	99.3
Lost taxes	182.0
Welfare payments	21.4
Total transfers	**302.7**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to total due to rounding.

7.5 DEADWEIGHT LOSS OF TAXATION PAYMENTS AND ADMINISTRATION

The $302.0 million in transfer payments (see Table 7.6) are not a net cost to society, as they represent a shift of resources from one group of individuals to another in society. For example, while consumers "gain" from paying less income tax, the government "loses" by receiving less income tax. When viewed from a societal perspective, the change in income tax is a zero-sum game.

However, as cancer in AYAs results in less government tax revenue and more government spending, the government will need to raise additional taxes from society. This is necessary to restore government taxation revenue to its original level, and also to fund the additional spending on top of this.

The act of raising taxes creates a distortion or "inefficiency" in the economy. This distortion is known as a DWL.

As shown in Figure 7.1, in the absence of taxes, society will supply and demand an optimal level of resources at Q0.

The imposition of additional taxes alters the price and quantity of goods sold compared to what they would be if the market were not distorted. The new intersection of supply and demand is at Q1 and P1, which is at a lower level of output. This means there is some diminution in the value of trade between buyers and sellers that would otherwise be enjoyed.

In a practical sense, this distortion reveals itself as a loss of efficiency in the economy, which means that raising $100 dollars of tax revenue requires consumers and producers to give up more than $100 of value. In order to calculate the size of this additional inefficiency which is needed to raise the $100 of tax revenue, Deloitte Access Economics' standard methodology is to apply rates used by the Productivity Commission in its study of distortions in the pharmaceutical industry (Productivity Commission, 2003). These rates are $0.275[20] per $1 of tax revenue raised, plus $0.0125 per $1 of tax revenue raised for Australian Taxation Office administration.

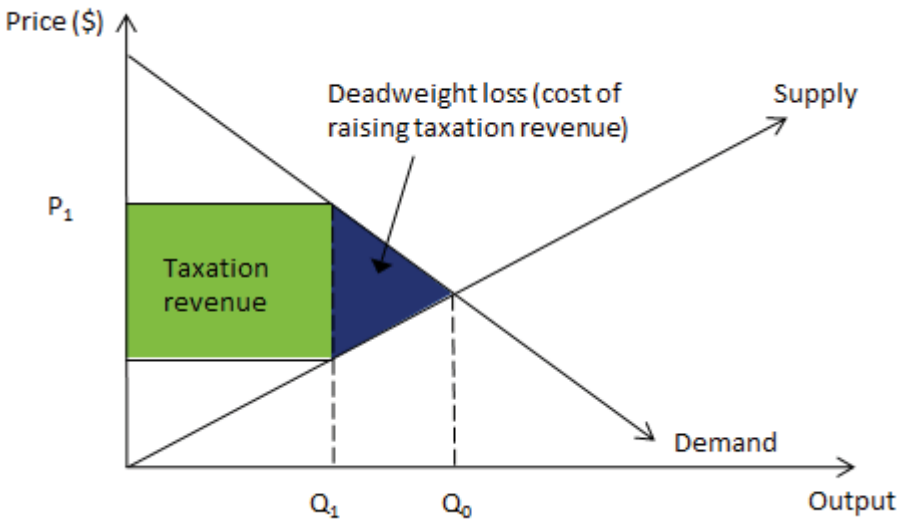
[20] Sensitivity testing on this rate could be performed at $0.15 (lower bound) and $0.40 (upper bound) (Productivity Commission, 2003).

The DWL rate was applied to:

- lost tax revenue from foregone earnings of people with cancer, their carers and employers (which must be raised from another source);
- welfare payments made to people with cancer and their carers; and
- government health system expenditure.

Thus, the $302.0 million in transfer payments result in a lifetime DWL to society of $87.0 million.
The $87.0 million is a net cost to society.

Figure 7.1: Deadweight loss of taxation



Source: Deloitte Access Economics.

8. Burden of disease costs

This chapter adopts the 'burden of disease' methodology in order to quantify the impact of cancer on wellbeing. The approach is non-financial, where pain, suffering and premature mortality are measured in terms of disability-adjusted life years (DALYs).

Key findings

The economic value of the burden of disease from all cancers in AYAs diagnosed in 2016 was estimated to be $701.4 million. This is equivalent to $0.6 million per AYA with cancer.

The cancer with the highest total burden of disease is brain cancer ($90.7 million, $1.7 million per person), followed by AML ($73.9 million, $2.0 million per person) and ALL ($66.6 million, $1.7 million per person).

8.1 VALUING LIFE AND HEALTH

The burden of disease as measured in DALYs can be converted into a dollar figure using an estimate of the value of a 'statistical' life (VSL). As the name suggests, the VSL is an estimate of the value society places on an anonymous life. Since Schelling's (1968) discussion of the economics of life saving, the economic literature has focused on willingness to pay (WTP) – or, conversely, willingness to accept – measures of mortality and morbidity, in order to develop estimates of the VSL.[21]

Estimates may be derived from observing peoples' choices in situations where they rank or trade off various states of wellbeing (loss or gain) either against each other or for dollar amounts, for example stated choice models of peoples' WTP for interventions that enhance health or willingness to accept poorer health outcomes or the risk of such states. Alternatively, risk studies use evidence of market trade-offs between risk and money, including numerous labour market and other studies (such as installing smoke detectors, wearing seatbelts or bike helmets, and so on).

The extensive literature in this field mostly uses econometric analysis to value mortality risk and the 'hedonic wage' by estimating compensating differentials for on-the-job risk exposure in labour markets; in other words, determining what dollar amount would be accepted by an individual to induce him/her to increase the probability of death or morbidity by a particular percentage.

In an attempt to overcome some of the issues in relation to placing a dollar value on a human life, a non-financial approach to valuing human life is used. Pain, suffering and premature mortality are measured in terms of DALYs, with 0 representing a year of perfect health and 1 representing death. This approach was developed by the WHO, the World Bank and Harvard University (Murray and Lopez, 1996). Methods and data sources are detailed further in Murray et al (2001).

The DALY approach has been adopted and applied in Australia by the AIHW. Mathers et al (1999) included separate identification of the premature mortality (years of life lost due to premature death – YLL) and morbidity (years of healthy life lost due to disability – YLD) components: ***DALYs = YLLs + YLDs***

In any year, the disability weight of a disease (for example, 0.18 for a broken wrist) reflects a relative health state. In this example, 0.18 would represent losing 18% of a year of healthy life because of the inflicted injury.

The DALY approach has been successful in avoiding the subjectivity of individual valuation and is capable of overcoming the problem of comparability between individuals and between nations, although nations have subsequently adopted variations in weighting systems. For example, in some countries DALYs are age-weighted, while in Australia the approach is taken to not age-weight DALYs, as occurs for the global burden of disease estimates.

[21] Note that while the focus in the literature has been on WTP, additional techniques have also been used to develop estimates of the VSL.

As DALYs are enumerated in years of life rather than in whole lives it is necessary to calculate the value of a 'statistical' life year (VSLY) based on the VSL. This is done using the formula:[22]

$$VSLY = \frac{VSL}{\sum_{i=o}^{n-1}(1+r)^i}$$

Where:

N = years of remaining life

R = discount rate

The Department of Prime Minister and Cabinet (2014) provided an estimate of the 'net' VSLY (that is, subtracting financial costs borne by individuals). This estimate was $182,000 in 2014, which inflates to around $184,732 in 2016 dollars for the VSLY.

A discount rate of 3% was used to estimate the future streams of the burden of disease from cancer, along with all other future streams in this report (see Section 3.3). Consideration of the discount rates used in the burden of disease calculations is necessary given recent updates to the Australian burden of disease methodology (AIHW, 2016b). A distinction needs to be made on the discount rate for future streams of DALYs (which are a measure of the number of years lost, not the monetary value of those years), and the discount rate for the associated monetary value of these streams (computed using the VSLY).

In this report, no discounting has been applied to future DALYs, consistent with the revised approach used by the AIHW and the WHO (AIHW, 2016b; Murray et al, 2012a). However, 3% discounting is applied to the corresponding VSLY in future years. It is necessary to discount the VSLY in future years for two key reasons:

- the VSLY as stipulated by the Department of Prime Minister and Cabinet is derived from the VSL using discounted future life years. If the future VSLY streams were not discounted in the burden of disease calculations, then in some situations the burden of disease from a condition could exceed the total VSL; and
- discounting the VSLY reflects that a dollar in the future has a lower value than one in 2016 due to positive time preference, risk and inflation.

[22] The formula is derived from the definition:VSL = ΣVSLYi/(1+r)i where i=0,1,2….n where VSLY is assumed to be constant (that is, no variation with age).

8.2 ESTIMATING THE BURDEN OF DISEASE FROM CANCER

In order to estimate the burden of disease from cancer, it was necessary to know the disability weight of each type of cancer, and the duration of time that is spent in each phase of cancer. Disability weights for different cancers in the respective phases were sourced from the 2013 study by the Global Burden of Disease Cancer Collaboration. The overall values for leukaemia were used for ALL and AML, and the overall values for lymphoma were used for HL and NHL.

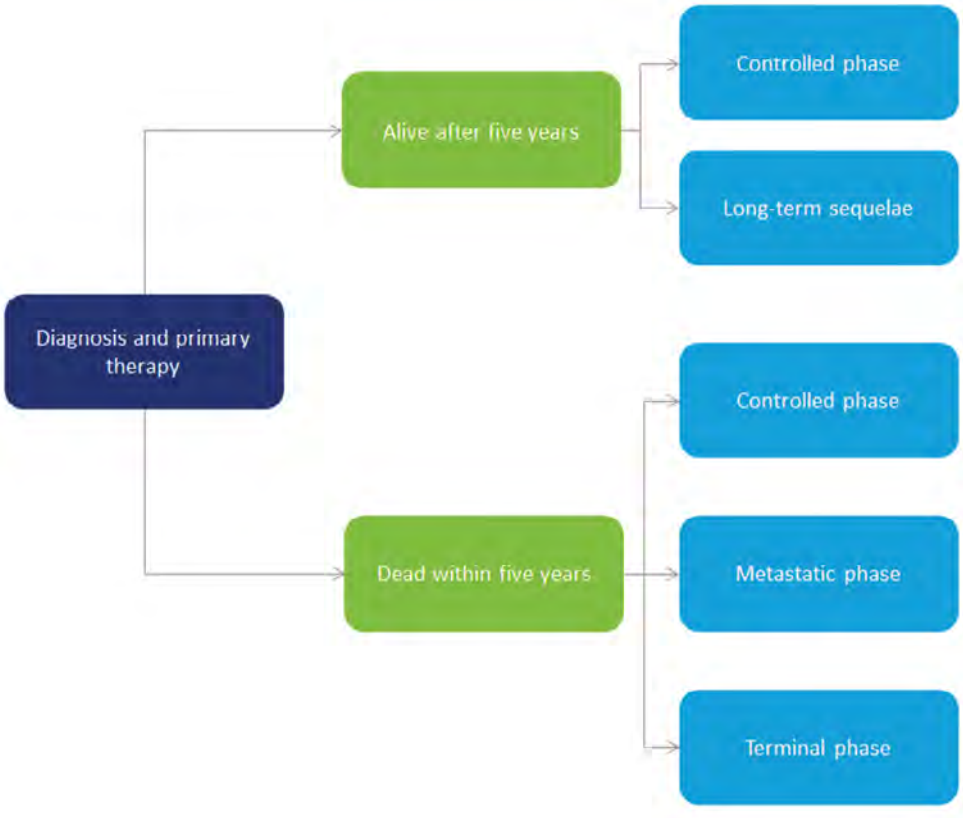
The WHO's methodology for calculating the burden of disease from cancer (which is also used by the AIHW) splits cancer into the following phases, as shown in Figure 8.1. For people who survive beyond five years, there are three phases:

- Diagnosis and primary therapy: in this phase, the cancer is diagnosed and successfully treated.
- Controlled phase: this phase is the time between the end of therapy and the five year mark.
- Long-term sequelae: this phase occurs after five years, and is the time spent with long-term health complications as a result of cancer (for example, traumatic brain injury among people who have had brain cancer).

For people who died within five years, there are four phases:

- Diagnosis and primary therapy: in this phase, the cancer is diagnosed and treated.
- Controlled phase:this phase is calculated as the mean survival time among terminal cases, less the time spent in the other three phases.
- Metastatic phase: in this phase, the cancer metastasises to other areas of the body.
- Terminal phase: this phase is defined as being one month prior to death.

Figure 8.1: Cancer phases



Source: Adapted from AIHW (2015b).

The duration of time spent in the diagnosis and treatment phase and the controlled phase for survivors were sourced from AIHW (2015b). Duration in the controlled phase for people with eventual deaths was estimated from Mathers et al (1999). The duration of the metastatic and terminal phase were sourced from the AIHW (2015b).

Table 8.1 shows the duration and disability weights used for all cancers combined. A more detailed table of duration and disability weights used for different cancers in different phases can be found in Appendix A.

Table 8.1: Duration and disability weights in phases of all cancer

Stage	Duration (years)	Disability weight
1: Diagnosis and treatment	0.3690	0.2880
2a: Controlled (survivors)	4.6310	0.0490
2b: Controlled (deaths)	3.3368	0.0490
3: Disseminated/metastatic	0.6326	0.4510
4: Terminal	0.0833	0.5545

Source: Deloitte Access Economics calculations based on AIHW (2016a).

In regards to the long-term sequelae, the burden of disease from this phase was not calculated due to insufficient data. The most recent Australian burden of disease publication (AIHW, 2016b) only includes long-term sequelae for one of the cancers which is disaggregated in this report (brain cancer). For this condition, long-term implications are limited to traumatic brain injury, which is classified into minor, medium and severe impacts. This long-term sequelae was a new addition to the Australian burden of disease methodology, and has not appeared in previous publications. As the 2016 report was released shortly before our analysis was undertaken, detailed working papers were not publicly available at the time this report was prepared. As such, key parameters were not available and so it was not possible to undertake these calculations.

The 2016 report also included long-term sequelae for several cancers which are not disaggregated in our analysis. These include laryngeal cancer (speech problems), bowel cancer (stoma), breast cancer (mastectomy), prostate cancer (impotence and urinary incontinence) and bladder cancer (urinary incontinence). The burden of disease from these long-term conditions was not calculated.

For all cancers combined, AYAs experienced:

- 398.2 YLDs, or 0.4 YLDs per person with cancer;
- 8,556.3 YLLs, or around 7.9 YLLs per person with cancer; and
- 8,954.5 DALYs overall or around 8.2 DALYs per person with cancer.

The economic value of the burden of disease from all cancers in AYAs was estimated to be $701.4 million in 2016. The relative proportions of YLDs (4%) and YLLs (96%) are reflective of the fact that YLDs are assumed to only occur within a period of 5 years maximum, while YLLs occur over the remaining life years that would have occurred in the absence of cancer. For AYAs who die from cancer, there are a large number of life years that would have occurred in the absence of cancer.

It was not possible to triangulate these estimates with the AIHW's 2016 burden of disease estimates (AIHW, 2016b) as this report does not provide sufficient granularity of results. Triangulation with previous Australian estimates from the AIHW (for example, Begg et al (2007)) is not useful given the significant methodological refinements to the burden of disease methodology for cancer that have occurred since this publication, such as the removal of long-term sequelae for some cancers, a reduction in disability weights, and the removal of discounting for DALYs. Table 8.2, Table 8.3 and Table 8.4 show the YLDs, YLLs and burden of disease disaggregated into different age groups and cancers.

Table 8.2: Estimated years of healthy life lost due to disability

Cancer type	Male	Female	People
Melanoma	23.3	31.3	**54.6**
AML	9.4	8.3	**17.7**
ALL	13.0	5.1	**18.2**
NHL	14.5	10.0	**24.5**
HL	22.6	22.2	**44.8**
Brain	15.0	10.7	**25.6**
Bone	9.7	3.9	**13.7**
Soft tssue	5.7	4.9	**10.6**
Testicular	39.2	0.0	**39.2**
Thyroid	5.1	20.2	**25.4**
Other	56.6	67.3	**124.0**
All Cancer	**214.3**	**184.0**	**398.2**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

Table 8.3: Estimated years of life lost due to premature death

Cancer type	Male	Female	People
Melanoma	209.3	320.2	**529.5**
AML	484.6	466.3	**950.9**
ALL	626.3	246.4	**872.8**
NHL	414.9	301.8	**716.7**
HL	147.4	175.0	**322.3**
Brain	659.5	513.8	**1,173.3**
Bone	622.8	284.6	**907.3**
Softtissue	256.4	249.5	**505.9**
Testicular	88.1	0.0	**88.1**
Thyroid	16.1	17.4	**33.5**
Other	1,091.4	1,364.6	**2,456.0**
All Cancer	**4,616.7**	**3,939.6**	**8,556.3**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

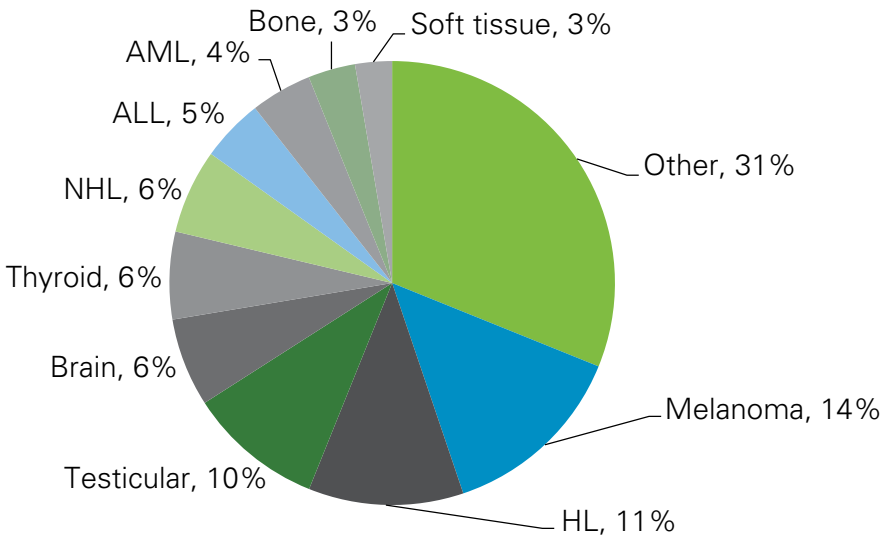
Table 8.4: Estimated burden of disease costs

Cancer type	Male ($m)	Female ($m)	People ($m)
Melanoma	19.4	29.0	**48.5**
AML	37.8	36.1	**73.9**
ALL	47.7	18.9	**66.6**
NHL	33.4	24.2	**57.6**
HL	14.7	16.5	**31.2**
Brain	51.2	39.5	**90.7**
Bone	46.8	21.3	**68.0**
Softtissue	19.8	19.1	**38.9**
Testicular	23.0	0.0	**23.0**
Thyroid	2.1	4.8	**6.9**
Other	82.4	113.6	**196.1**
All Cancer	**378.3**	**323.1**	**701.4**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

Chart 8.1 shows that of the cancer categories analysed in this report, melanoma has the highest amount of YLDs, followed by HL and testicular cancer. This is consistent with these cancers having the highest incidence (see Chapter 4), given that the disability weights for each cancer are the same.

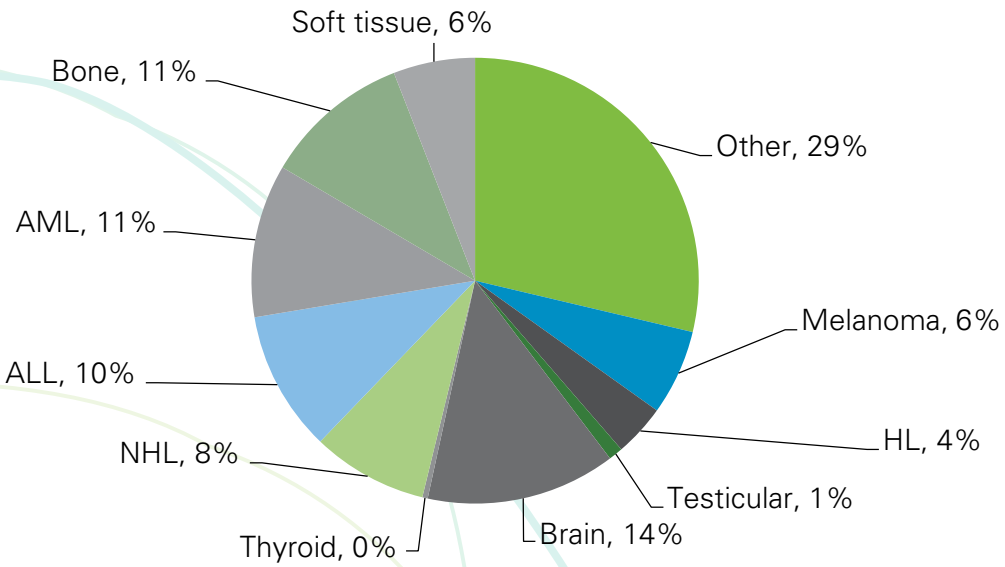
Chart 8.1: Distribution of total YLDs



Source: Deloitte Access Economics calculations.

Chart 8.2 shows that YLLs are highest for brain cancer, ALL and AML. This finding is consistent with the relatively high mortality rates, and low relative survival rates, for these cancers, as outlined in Chapter 4.

Chart 8.2: Distribution of total YLLs



Source: Deloitte Access Economics calculations.

9. Summary

This chapter summarises the total costs of cancer in AYAs, expressed in 2016 dollars.

Key findings

In 2016, it is estimated that almost 1,100 AYAs will be diagnosed with cancer, and approximately 112 AYAs will die as a result of cancer.

For AYAs who are diagnosed with cancer in 2016, the total lifetime costs were estimated to be $1.4 billion, or $1.3 million per person. This is comprised of $741.9 million in economic costs and $701.4 million in burden of disease costs.

The total lifetime cost of cancer among AYAs diagnosed in 2016 is $1.44 billion, as shown in Table 9.1. Of the total costs, burden of disease constitutes 48.6%, productivity costs of AYAs 31.6%, health system costs 10.1%, DWL 6.0% and informal carer costs 3.7% (Chart 9.1).

Table 9.1: Estimated total lifetime costs of cancer in AYAs

Component	Value ($m)	Per person ($'000)
Health system costs	146.5	134.6
Productivity costs (AYAs)	455.7	418.7
Carercosts	52.7	48.4
DWL (proportion of transfer costs)	87.0	80.0
Burden of disease	701.4	644.5
Total costs	**1,443.3**	**1,326.1**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

It is important to note that the costs of cancer are many and varied, and the following costs were out of scope for this analysis: educational impacts, presenteeism (reduced productivity while at work), health system costs that occur more than five years after diagnosis, government programs, formal care, travel, clinical trials conducted by the private sector, and funeral costs brought forward. As such, the costs in Table 9.1 should be viewed as a conservative estimate of the impact of cancer in AYAs.

The most cost is experienced by individuals (70.6%, for example through the burden of disease, reduced workforce participation and premature mortality), followed by government (19.5%, such as through health expenditure), as shown in Chart 9.2.

Aside from the burden of disease, the costs from premature mortality ($162.0 million) and reduced workforce participation ($290.1 million) are the largest single component of the costs from cancer. The high premature mortality costs are reflective of the fact that cancer is the leading cause of disease-related deaths among AYAs (AIHW, 2016b).

Table 9.2 shows the total lifetime cost by component and cancer type. Of the cancers in this analysis, brain cancer has the highest proportion of total costs (11.1%) followed by AML (8.9%).

Chart 9.1: Costs associated with cancer in AYAs

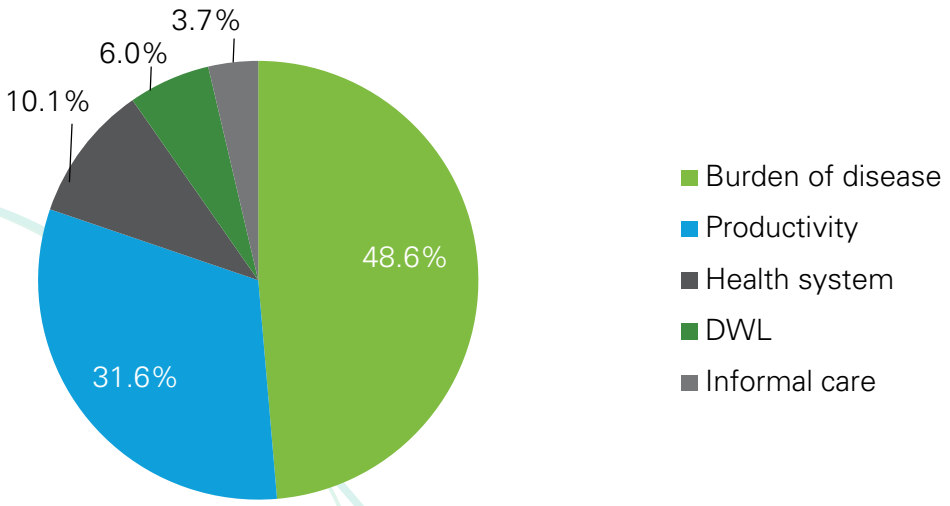
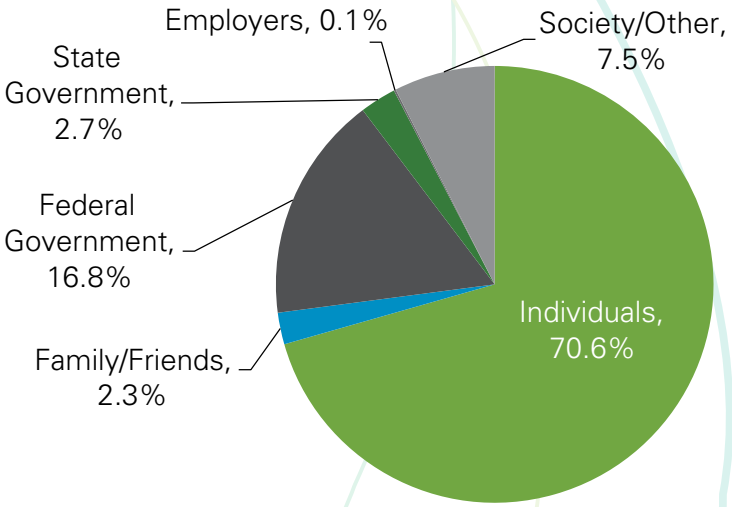


Chart 9.2: Distribution of total costs



On a per person basis, Table 9.3 shows that the highest per person cost is attributable to AML ($3.4 million), followed by ALL ($3.1 million) and brain cancer ($3.0 million), with the lowest cost per person experienced by AYAs with thyroid cancer ($0.4 million).

Table 9.2: Estimated total lifetime costs

Cancer type	Expenditure component ($m)					
	Health System costs	*Productivity costs*	*Carer costs*	*DWL*	*Burden of disease*	*Total*
Melanoma	2.7	48.6	8.7	6.5	48.5	**114.9**
AML	17.1	28.1	2.0	6.6	73.9	**127.7**
ALL	17.6	30.5	2.5	7.0	66.6	**124.2**
NHL	8.0	36.7	3.2	5.7	57.6	**111.3**
HL	6.3	43.1	6.4	6.4	31.2	**93.5**
Brain	7.4	50.2	3.2	8.0	90.7	**159.5**
Bone	9.7	33.9	2.5	5.7	68.0	**119.8**
Softtissue	5.2	18.0	2.0	3.1	38.9	**67.2**
Testicular	2.3	49.1	5.9	6.2	23.0	**86.5**
Thyroid	0.7	20.4	3.8	2.7	6.9	**34.5**
Other	69.4	97.4	12.4	29.2	196.1	**404.6**
All Cancer	**146.5**	**455.7**	**52.7**	**87.0**	**701.4**	**1,443.3**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

Table 9.3: Estimated total lifetime costs per person

Cancer type	Expenditure component ($'000)					
	Health System costs	*Productivity costs*	*Carer costs*	*DWL*	*Burden of disease*	*Total*
Melanoma	13.7	251.1	45.2	33.4	250.4	**593.8**
AML	452.8	741.1	53.4	174.4	1,958.5	**3,380.2**
ALL	447.8	763.4	62.5	176.7	1,693.0	**3,143.4**
NHL	116.0	530.5	47.0	83.1	832.8	**1,609.4**
HL	45.2	306.4	45.6	45.6	221.8	**664.5**
Brain	140.8	951.2	60.6	151.2	1,720.2	**3,024.0**
Bone	237.8	831.3	62.2	140.3	1,668.2	**2,939.8**
Softtissue	156.2	541.0	59.9	93.2	1,168.5	**2,018.9**
Testicular	17.2	369.0	44.0	46.3	173.2	**649.8**
Thyroid	7.6	229.4	42.7	30.2	77.7	**387.6**
Other	267.6	377.2	48.0	112.7	755.6	**1,561.1**
All Cancer	**134.6**	**418.7**	**48.4**	**80.0**	**644.5**	**1,326.1**

Source: Deloitte Access Economics calculations.
Note: Numbers may not sum exactly to totals due to rounding.

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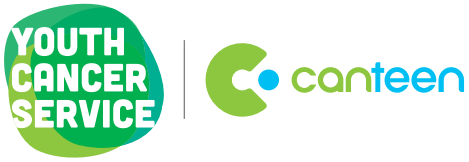
Table A.1: Cancer durations and disability weights

	Duration (years)	Disability weight
Sequelae 1– Diagnosis and treatment		
Melanomas	0.0890	0.28800
Leukaemia	0.6667	0.28800
Lymphoma	0.3333	0.28800
Brain	0.2500	0.28800
Bone	0.1667	0.28800
Soft tissue	0.1667	0.28800
Testicular	0.2500	0.28800
Thyroid	0.1667	0.28800
All others	0.3690	0.28800
Sequelae 2a – controlled (survivors)		
Melanomas	4.9110	0.04900
Leukaemia	4.3333	0.04900
Lymphoma	4.6667	0.04900
Brain	4.7500	0.04900
Bone	4.8333	0.04900
Soft tissue	4.8333	0.04900
Testicular	4.7500	0.04900
Thyroid	4.8333	0.04900
All others	4.6310	0.04900
Sequelae 2b – controlled (deaths)		
Melanomas	6.2284	0.04900
Leukaemia	1.3914	0.04900
Lymphoma	3.5095	0.04900
Brain	0.0000	0.04900
Bone	1.1570	0.04900
Soft tissue	1.1570	0.04900
Testicular	1.2100	0.04900
Thyroid	2.1703	0.04900
All others	3.3368	0.04900

	Duration (years)	Disability weight
Sequelae 3 – Metastatic		
Melanomas	0.5583	0.45100
Leukaemia	0.5917	0.45100
Lymphoma	0.6292	0.45100
Brain	1.5833	0.45100
Bone	0.6250	0.45100
Soft tissue	0.6250	0.45100
Testicular	0.7667	0.45100
Thyroid	0.5333	0.45100
All others	0.6326	0.45100
Sequelae 4 – Terminal		
Melanomas	0.0833	0.55450
Leukaemia	0.0833	0.55450
Lymphoma	0.0833	0.55450
Brain	0.0833	0.55450
Bone	0.0833	0.55450
Soft tissue	0.0833	0.55450
Testicular	0.0833	0.55450
Thyroid	0.0833	0.55450
All others	0.0833	0.55450

Source: AIHW (2015b) and Mathers et al (1999).



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