



# Review of cancer among Aboriginal and Torres Strait Islander people

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## Introduction

Cancer is a major cause of illness in Australia and has substantial social and economic impacts on individuals, families and the community [1]. Findings from the Australian Burden of Disease Study showed that cancer was the greatest cause of health burden in Australia. Socially disadvantaged groups and Indigenous people are particularly at risk, Aboriginal and Torres Strait Islander people experience nearly twice the cancer burden of non-Indigenous people. The most common cancers diagnosed among Aboriginal and Torres Strait Islander people are lung, breast (females), bowel and prostate (males) [2].

Cancer is the term used for a variety of diseases that cause damage to the DNA (genetic blueprint) of the cells resulting in uncontrolled growth (cells normally grow and multiply in a controlled manner) [3]. If cells spread into surrounding areas or to different parts of the body (metastasise), this invasion is known as malignancy. A benign growth is a mass of cells that doesn't spread to surrounding areas or metastasise. Malignant (cancerous) or benign (non-cancerous) abnormal tissue growths may both be referred to as neoplasms. Cancerous cells can arise from almost any cell, so cancer can occur almost anywhere in the body [4]. Different types of cancer are distinguished by the location in the body where the disease began (for example, lung) or by the cell type involved (for example, basal cell carcinoma).

## About this review

The purpose of this review is to provide a comprehensive synthesis of key information on cancer among Aboriginal and Torres Strait Islander people in Australia to: (1) inform those involved or interested in Aboriginal and Torres Strait Islander health; and (2) provide the evidence for those involved in policy, strategy and program development and delivery. The review provides general information on factors that contribute to cancer among Aboriginal and Torres Strait Islander people. It provides detailed information on the extent of cancer among Aboriginal and Torres Strait Islander people, including: incidence, prevalence and survival data; mortality and burden of disease and health service utilisation. This review discusses the issues of prevention and management of cancer, and provides information on relevant programs, services, policies and strategies that address cancer among Aboriginal and Torres Strait Islander people. It concludes by discussing possible future directions for combatting cancer in Australia.

This review draws mostly on journal publications, government reports, national data collections and national surveys, the majority of which can be accessed through the HealthInfoNet's Australian Indigenous library (<https://healthinfonet.ecu.edu.au/key-resources/publications>).

When referring to Australia's Indigenous people, the HealthInfoNet prefers to use the terms Aboriginal, Torres Strait Islander, or Aboriginal and Torres Strait Islander. However, when referencing information from other sources, authors may use the terms from the original source unless they can obtain clarification from the report authors/copyright holders. As a result, readers may see these terms used interchangeably with the term 'Indigenous' in some instances.

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## Summary

Cancer is a disease often associated with ageing, with incidence and mortality rates increasing in older age groups. As life expectancy increases, Australia's population is ageing, so cancer incidence rates have also increased. Aboriginal and Torres Strait Islander people often have a higher incidence of health conditions at a younger age than their non-Indigenous peers, for cancer however, the age-standardised incidence of cancer overall is higher for Aboriginal and Torres Strait Islander than for non-Indigenous people from the age of about 45 years. For a number of cancers Aboriginal and Torres Strait Islander people have a lower incidence. These cancers include breast cancer, prostate cancer and non-Hodgkin lymphoma. Many of these cancers are considered to be preventable.

### Risk factors for cancer

Tobacco smoking is the greatest risk factor for cancer, and smoking-related cancers generally have a much poorer prognosis. Cancers caused by smoking include lung, oesophagus, larynx, mouth, throat, kidney, bladder, liver, pancreas, cervix and stomach. Aboriginal and Torres Strait Islander people continue to have markedly higher rates of tobacco smoking, although this is an area where government and community-based interventions have been sustained over a number of years. It appears that there may be a decrease in smoking prevalence in urban areas although whether an impact is occurring in more remote areas is less clear. There is a need to persist with the efforts at reducing the uptake of smoking in youth and to support smoking cessation programs.

A group of cancers with higher incidence in Aboriginal and Torres Strait Islander people are those related to high alcohol consumption. While overall, Aboriginal and Torres Strait Islander people are less likely to consume alcohol than non-Indigenous people, many of those who drink consume at levels considered harmful to health. Binge drinking and regular heavy alcohol consumption are risks for breast, bowel, liver and oral cancers. The risk of alcohol-related cancers is much higher in people who also smoke, with the risks multiplicative not just additive.

Some infections can be risk factors for cancer. A major risk factor for liver cancer is chronic infection with hepatitis B or with hepatitis C, both infections have higher rates in the Aboriginal and Torres Strait Islander population. Immunisation for hepatitis B and improved treatments for hepatitis C aim to reduce these risks. Infection with certain subtypes of the Human Papilloma Virus (HPV) can cause the development of cervical cancer. The implementation of HPV vaccination programs, which help protect against the subtypes of virus known to have the greatest association with cervical cancer, will greatly reduce the incidence of cervical abnormalities and cervical cancer over time.

Poor nutrition, being overweight or obese and having low levels of physical activity are other risk factors for cancer. All forms of physical activity protect against some cancers, as well as against weight gain. The risk for some cancers increases with weight gain, overweight and obesity, independent of the level of physical activity. Many Aboriginal and Torres Strait Islander adult people don't eat enough fruit and vegetables, are overweight or obese and don't get enough physical activity. In remote communities, the contemporary diet of Aboriginal and Torres Strait Islander people tends to be very low in fruit and vegetable content, high in energy and sugars, and moderately high in fats.

These risk factors, sometimes termed 'lifestyle' or 'behavioural', are known to be strongly influenced by the social determinants of health. These refer to the economic opportunities, physical infrastructure and social conditions that influence the health of individuals and communities, and reflect the substantial disadvantages experienced by Aboriginal and Torres Strait Islander people in comparison with non-Indigenous people. These disadvantages are evident in measures of education, employment, income, housing, access to services and incarceration. This is underpinned by the dispossession which accompanied colonisation and ongoing marginalisation, racism and child removal which have had an enduring impact on the health status of Aboriginal and Torres Strait Islander people.

Social and cultural determinants not only influence risk factors for cancer but also health seeking behaviour and therefore participation in cancer screening programs, willingness to present to health providers with symptoms and the timeliness of diagnosis and uptake and adherence to recommended treatment.



## Screening

Australia has three national population-based screening programs for breast, bowel and cervical cancers, all of which aim to reduce morbidity and mortality through early detection:

- BreastScreen Australia, the national breast screening program. Aboriginal and Torres Strait Islander women have been under-screened and this has been a consistent finding.
- the National Bowel Cancer Screening Program (NBCSP). The participation rate for Aboriginal and Torres Strait Islander people has been well below that for non-Indigenous people.
- the National Cervical Screening Program. A new approach to screening based upon a HPV cervical screening test was implemented in December 2017. Regular cervical screening protects against cervical cancer by detecting HPV which in rare cases can lead to cell changes in the cervix. Previously the Pap (Papanicolaou) test was used. Generally, Aboriginal and Torres Strait Islander women have been under-screened.

## Cancer mortality and treatment uptake

While once a diagnosis of cancer was considered a death sentence, there have been progressive breakthroughs in the diagnosis and management of cancer over the last few decades. With earlier diagnosis and improved treatments, including surgery, chemotherapy, immunotherapy and radiotherapy, there are many more options for cancer treatment. Many cancer survivors have been cured and even those who eventually succumb to their disease can have many years with a high quality of life.

Unfortunately, Aboriginal and Torres Strait Islander people have not experienced the benefits of modern cancer treatments to the same extent as non-Indigenous people. Survival information shows that Aboriginal and Torres Strait Islander people experienced substantially lower five-year crude survival rates across all age groups compared with non-Indigenous people. For both population groups, the five-year crude survival rate fell with age. This deficit in survival was true across all types of cancer.

While to some extent this survival disparity reflects higher rates of cancer with a poor prognosis and later staging at diagnosis, this does not account for all of the difference in survival rates and attention must turn to the way in which health services meet the needs of Aboriginal and Torres Strait Islander people.

There is increasing literature around some of the challenges for Aboriginal and Torres Strait Islander people in access and uptake of cancer treatments. Distance and poor availability of services with increasing remoteness present barriers to accessing health care services. The lack of cancer services in regional and remote areas, where there is a higher proportion of Aboriginal and Torres Strait Islander people in the population, contributes to the particularly poor outcomes of patients living in those areas. Factors such as the location and accessibility of health services have been shown to influence the extent to which Aboriginal and Torres Strait Islander people present for diagnosis and continue with treatment. Radiotherapy services are generally located in large population centres and this may mean patients forego this as a treatment even when recommended because it would require many weeks away from their home and family.

In addition to logistical difficulties, other barriers to the use of cancer health services by Aboriginal and Torres Strait Islander people have been described. There are substantial costs associated with cancer treatment including consultation fees, medicines, transport and lost wages. When people travel from remote areas to a metropolitan hospital, there may be less understanding of their culture and needs, and separation from land and family is more acutely experienced. Collaboration and integration across different parts of the health system are often suboptimal and many Aboriginal and Torres Strait Islander people will have a fear or lack of trust of mainstream health services based upon personal experience or collective memory. Cultural misunderstandings, poor communication and experiences of discrimination by mainstream practitioners have been commonly documented. There is often poor understanding of Aboriginal cultural beliefs, including fatalistic or differing cultural beliefs about cancer, and that a diagnosis of cancer may be associated with feelings of shame.

The first National Aboriginal and Torres Strait Islander Cancer Framework, released in 2015 by Cancer Australia, reinforces that culturally safe services and a culturally competent workforce are considered core requirements for improving Aboriginal and Torres Strait Islander cancer outcomes. Culturally appropriate cancer care is based upon strong therapeutic relationships between patients and tertiary and primary health professionals and cross-cultural knowledge and expert skills on the part of health professionals. It is recommended that cultural competence training is made available to all staff members to help improve communication and quality of care provided and to ensure that Aboriginal and Torres Strait Islander people are not discouraged from presenting. Health care providers who understand the beliefs and perspectives of Aboriginal and Torres Strait Islanders regarding cancer will be better placed to build an appropriate therapeutic relationship in cancer-related consultations.

Aboriginal and Torres Strait Islander cancer support groups have been identified as important for improving cancer awareness and increasing participation in cancer screening services. Aboriginal women attending these support groups have reported an increased understanding of screening and reported less fear and concern over cultural appropriateness, with increases in screening rates. Support groups also can help in follow up and ongoing care for cancer survivors, particularly where they are tailored to meet the needs of Aboriginal and Torres Strait Islander people.

## Policies to address Aboriginal cancer disparities

Increasingly there has been recognition of the disparities that exist in Aboriginal cancer outcomes and the need for concerted efforts to overcome these. The National Aboriginal and Torres Strait Islander Cancer Framework (Framework) provides guidance for individuals, communities, organisations and governments and outlines seven priority areas for action:

- improving knowledge and attitudes about cancer
- focusing prevention activities
- increasing participation in screening and immunisation
- ensuring early diagnosis
- delivering optimal and culturally appropriate treatment and care
- involving, informing and supporting families and carers
- strengthening the capacity of cancer-related services to meet the needs of Aboriginal and Torres Strait Islander people.

Addressing the various factors that contribute to the development and better treatment of cancer among Aboriginal and Torres Strait Islander people is important. Improvements in these areas, particularly in behavioural risk factors, are likely to take some time to be reflected in better outcomes. However, each of the Framework priorities was accompanied by a number of enablers to assist in planning or reviewing strategies to address that priority. The enablers provide flexible approaches to meeting the priorities that allow for local context and needs. The development of the Framework has created a high level of expectation around the ability to address cancer disparities. The Wellbeing Framework for Aboriginal and Torres Strait Islander Peoples Living with Chronic Disease, published in 2015, aims to assist healthcare services to improve the quality of life and health outcomes for Aboriginal and Torres Strait Islander people living with chronic disease. It aims to achieve this goal by improving the quality of care through more supportive and culturally appropriate care that the physical aspects.

Current deficiencies in the prevention and management of cancer in Aboriginal and Torres Strait Islander people suggest there is considerable scope for better services that should lead to improvements in the short to medium term. Effective cancer prevention and management programs, that are tailored to community needs and are culturally appropriate, are vital for the current and future health of Aboriginal and Torres Strait Islander people. As with all complex health conditions, this requires improved access to and integration of high quality primary health care services and tertiary specialist services.

## Key facts

### The context for cancer among Aboriginal and Torres Strait Islander people

- Factors contributing to cancer outcomes among Aboriginal and Torres Strait Islander people reflect a combination of broad historical influences, and social and cultural determinants, as well as proximal health risk factors and the delivery of cancer services.
- Many cancer risk factors are more common in Aboriginal and Torres Strait Islander people than other Australians, including: consuming alcohol at risky levels; smoking; and being overweight or obese.

### Extent of cancer among Aboriginal and Torres Strait Islander people

- Aboriginal and Torres Strait Islander people generally have lower cancer prevalence than non-Indigenous people.
- Five year survival is lower for Aboriginal and Torres Strait Islander people than for non-Indigenous people.
- Lung cancer is the most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people, followed by breast cancer (females), bowel cancer and prostate cancer (males).

- Aboriginal and Torres Strait Islander people have lower hospitalisation rates than non-Indigenous people for a principal diagnosis of cancer.
- Mortality rates among Aboriginal and Torres Strait Islander people are higher than for non-Indigenous people.
- Cancer is the third most common contributor to fatal burden for Aboriginal and Torres Strait Islander people. Lung cancer comprises the largest proportion of the fatal burden due to cancer.

### Prevention and management

- Culturally appropriate, locally supported, targeted intensive lifestyle programs are recommended for Aboriginal and Torres Strait Islander people to provide participants with the life skills, knowledge and support needed to make sustainable lifestyle changes to prevent the onset of cancer.
- Effective cancer management through early detection programs, a culturally competent workforce, cancer support groups, assessment of the unmet support needs of patients diagnosed with cancer and improved links between Aboriginal and Torres Strait Islander communities, primary health care providers and mainstream cancer care services could assist in sustained improvements in cancer care and health outcomes for Aboriginal and Torres Strait Islander people.

### Programs and services

- Government-funded, population based screening activities for the early detection of cancer include BreastScreen Australia, the National Bowel Cancer Screening Program, and the National Cervical Screening Program. To increase participation in screening programs, there is a need for flexibility in the delivery of these services to ensure they are culturally sensitive and appropriate to the knowledge, attitudes and beliefs of Aboriginal and Torres Strait Islander people.

### Policies and strategies

- The first National Aboriginal and Torres Strait Islander Cancer Framework was released in 2015, to address disparities and improve cancer outcomes for Aboriginal and Torres Strait Islander people.

## The context for cancer among Aboriginal and Torres Strait Islander people

The risk of developing cancer is influenced not only by an individual's age, family history and behaviour [5], but also by historical, socioeconomic, cultural and geographical factors [6]. Cancer exists alongside a number of determinants that influence the health of individuals, including the physical, economic and social environments in which people live. This is particularly the case for Aboriginal and Torres Strait Islander people who still suffer from the consequences of European settlement, in particular the impact of infectious and chronic diseases, and social dislocation. These factors, considered historical in origin, have been perpetuated by the contemporary social and cultural determinants of health that contribute to current Aboriginal and Torres Strait Islander health inequalities [7]. To understand the impact of cancer on Aboriginal and Torres Strait Islander people, it is necessary to understand the historical, social and cultural context and the demographic factors related to Aboriginal and Torres Strait Islander health.

### Historical, socioeconomic and cultural context

Aboriginal and Torres Strait Islander people, the first populations of Australia, traditionally had hunter-gatherer lifestyles but the arrival of Europeans in 1788 led to major changes [7]. Activities such as traditional ways of finding food and resources, cultural practices and sustaining the spiritual connection to land changed over time [7-9]. The decline in these practices, combined with an increase in Western lifestyles, set within a context of colonisation which promoted dispossession, marginalisation, racism and Stolen Generations, have had an enduring impact on the health status of Aboriginal and Torres Strait Islander people [7, 10-13]. Adverse changes in physical activity and nutrition, combined with the introduction of alcohol and tobacco (all key risk factors for cancer), played an important role in the development of cancer in Aboriginal and Torres Strait Islander people, particularly in the second half of the 20th century [14, 15].

Economic opportunity, physical infrastructure and social conditions are known to influence the health of individuals and communities [16-18]. In terms of all of these factors, Aboriginal and Torres Strait Islander people suffer substantial disadvantage in comparison with non-Indigenous people, evident in measures of education, employment, income, housing, access to services, connection with land, racism, and incarceration.

The knowledge, attitudes and beliefs which Aboriginal and Torres Strait Islander people hold in relation to cancer can have a negative impact on health seeking behaviours, such as participation in screening programs and in making decisions around cancer treatment. It is probable that a lack of knowledge about cancer exists and there is poor understanding of its causes, available treatments and likelihood of survival [19]. Feelings of 'shame' around cancer and perceptions of culturally unsafe health services are common. High mortality rates from cancer and few public stories of survivorship may have led to fatalistic attitudes and cancer being associated with lack of survival [19-21]. Some traditional beliefs around cancer are that it is a form of punishment for a past misdeed [20], the fault of 'white man' as it was not a concern before colonisation [19] or that it is contagious [19, 20] but how widespread such beliefs are in the contemporary world is unknown.

### Demographic factors

In 2016, the Aboriginal and Torres Strait Islander population was estimated to be 744,956 people, comprising 3.1% of the total Australian population and ranging from 0.9% of the total population in Victoria to 30% in the Northern Territory (Table 1) [22, 23]. The majority of Aboriginal and Torres Strait Islander people lived in New South Wales and Queensland (Table 1).

It is estimated that in 2016, around 35% of Aboriginal and Torres Strait Islander people (262,297 people) lived in major cities, 45% (333,238 people) lived in inner and outer regional areas and 20% (149,421 people) lived in remote and very remote areas [22].

The Aboriginal and Torres Strait Islander population is younger than the non-Indigenous population: 34% are aged less than 15 years (compared with 19% non-Indigenous), and only 4% are aged 65 and over (compared with 15% non-Indigenous) (Derived from [22, 24]).

Table 1. Estimated Indigenous (Aboriginal and Torres Strait Islander) population, by jurisdiction, Australia, 30 June 2016

Jurisdiction	Indigenous population (number)	Proportion of Australian Indigenous population (%)	Proportion of jurisdiction population (%)
New South Wales (NSW)	229,951	31	3.0
Victoria (Vic)	53,663	7.2	0.9
Queensland (Qld)	213,160	29	4.3
Western Australia (WA)	97,681	13	3.5
South Australia (SA)	41,515	5.6	2.4
Tasmania (Tas)	27,052	3.6	5.2
Australian Capital Territory (ACT)	7,103	1.0	1.8
Northern Territory (NT)	74,543	10	30
Australia	744,956	100	3.1

Note: Australian population includes Jervis Bay Territory, the Cocos (Keeling) Islands, and Christmas Island

Source: Derived from ABS, 2014 [22], ABS, 2016 [23]

## Factors contributing to cancer occurrence

Factors contributing to cancer among Aboriginal and Torres Strait Islander people reflect a combination of broad historical influences and social and cultural determinants, as well as proximal health risk factors and the delivery of cancer services. It is beyond the scope of this review to discuss the underlying social and cultural determinants that influence the development of cancer or the role of genetics but the main health risk factors are discussed below.

Several behavioural and external factors are known to increase the risk of developing cancer. These include alcohol consumption, smoking, poor nutrition, being overweight or obese, infectious diseases, environmental factors and radiation [5].

### Health risk factors for cancer

Health risk factors refer to the behaviours, characteristics, or exposures that increase the likelihood of a person developing cancer. When people have multiple risk factors, the likelihood of developing the disease is heightened. Risk factors can also increase the severity of the disease and the likelihood of developing complications or other diseases. However, some people with one or more risk factors may never develop cancer and other people who do develop cancer have no apparent risk factors [25].

Risk factors for cancer can be divided into two types – modifiable risks and non-modifiable risks. Modifiable risk factors are those that can be modified by changes to behaviour and lifestyle, such as smoking, poor nutrition and low levels of physical activity. Non-modifiable means those risk factors that cannot be changed, such as age or family history. Different kinds of cancer have different risk factors, but a number of cancers share common risk factors.

Aboriginal and Torres Strait Islander people are more likely to have lifestyle and behavioural risk factors for cancer than non-Indigenous people and many who have cancer have multiple risk factors and other related health problems [26]. The high prevalence of some risk factors among Aboriginal and Torres Strait Islander people is likely to contribute to the high incidence of some cancers in this population compared with the non-Indigenous population [27].

## Alcohol consumption

Although Aboriginal and Torres Strait Islander people are less likely than non-Indigenous people to drink alcohol, those who drink are more likely to do so at risky levels [28, 29]. The 2012–2013 Aboriginal and Torres Strait Islander Health Survey (AATSIHS) reported that among Aboriginal and Torres Strait Islander people aged 18 years and over who drank alcohol, 20% drank at levels exceeding the 2009 guidelines for long-term/lifetime drinking risk [30].

Related cancers: bowel, breast, oral cavity and pharynx, larynx, oesophagus, liver [4].

## Smoking and passive smoking

The National Aboriginal and Torres Strait Islander Social Survey, 2014–15 reported that Aboriginal and Torres Strait Islander people were 2.8 times more likely to smoke than non-Indigenous people (39% compared with 14% respectively) [31]. Exposure to passive smoking is also high, with 19% of Aboriginal and Torres Strait Islander people aged 15 years and over and 13% of Aboriginal and Torres Strait Islander children aged 0–14 years living in a household in which someone smokes inside.

Related cancers: lung, oral cavity and pharynx, bowel, oesophagus, bladder, kidney and ureter, pancreas, larynx, nasal cavity, stomach, liver, cervical, ovary, bones and bone marrow (myeloid leukaemia), childhood cancers (from second hand smoke) [32].

## Nutrition

The 2012–2013 AATSIHS, reported that slightly more than half, 54%, of Aboriginal and Torres Strait Islander people were eating enough fruit each day, and only 8% were eating enough vegetables [33]. The contemporary diet of Aboriginal and Torres Strait Islander people in remote communities tends to be very low in fruit and vegetable content, high in energy and sugars, and moderately high in fats [34].

Related cancers: bowel, lung, oesophagus, oral cavity and pharynx, stomach, larynx [32].

## Overweight and obesity

It is estimated that 71% of the Aboriginal and Torres Strait Islander adult population is overweight or obese, and 65% are not getting enough physical activity [35]. The 2012–2013 AATSIHS reported that Aboriginal and Torres Strait Islander people aged 15 years and over were 1.2 times more likely than non-Indigenous people to be overweight or obese [36–38].

Related cancers: oesophagus, pancreas, bowel, breast (in post-menopausal women), endometrium, kidney, gallbladder [32].

## Infectious diseases

Chronic infectious diseases interact with human cells and the immune system in a way that can sometimes cause the development of cancer. Human Papilloma Virus (HPV) is a common sexually transmitted infection (STI) and some types of HPV can persist and cause cervical cancer [39]. The implementation of HPV vaccination programs, which help protect against the subtypes of virus known to have the greatest association with cervical cancer, will greatly reduce the incidence of cervical abnormalities and cervical cancer over time. An immunisation program is universally delivered at schools in Australia. Boys and girls aged 12–13 years are given the vaccination which is funded under the National Immunisation Program [40].

The prevalence of Hepatitis B Virus (HBV), a leading cause of liver cancer in Australia, is higher for Aboriginal and Torres Strait Islander people than for non-Indigenous people [41]. In the past, hepatitis B was often acquired in infancy or early childhood when it was more likely to become chronic. Steps that can prevent transmission have now been in place for many years. However, it will take several decades to

fully realise the benefits from the implementation of a universal infant hepatitis B vaccination program to protect against chronic infection with hepatitis B virus, which causes liver cancer in later life.

Hepatitis C is also a cause of liver cancer and Aboriginal and Torres Strait Islander people are at risk as it is associated with incarceration and injecting drug use due to sharing injecting equipment [41]. The challenges associated with treatments for hepatitis C have been greatly reduced over the last few years with new treatments showing remarkable results in terms of eliminating hepatitis C virus infection, as well as having treatment that is easier and less toxic, increasing successful completion rates.

## Risk factors by cancer types

A summary of the risk factors for each of the most common types of cancer is set out below (Table 2).

Table 2. Summary of risk factors by cancer type

Cancer type	Breast	Cervical	Prostate	Bowel	Lung	Liver	Oral	Skin
<b>Risk factor</b>								
Alcohol	✓			✓		✓	✓	
Smoking/passive smoking		✓		✓	✓	✓	✓	
Diet			✓	✓				
Overweight and obesity	✓			✓		✓		
Infectious diseases		✓			✓	✓	✓	
Family history and genetic susceptibility	✓		✓	✓				
Occupational exposure/environmental					✓	✓	✓	
UV radiation								✓

Sources: AIHW, 2013 [26], Moon, et al., 2017 [4], The Kirby Institute, 2017 [41], Castles, et al., 2016 [5]

## Risk assessment tools for cancer

A number of risk assessment tools have been developed by Cancer Australia. Although these are not designed specifically for Aboriginal and Torres Strait Islander people, they are suitable to their needs. One of these tools, Check your cancer risk, assesses the risk of an individual developing cancer as a result of lifestyle choices and provides tips for healthy living [42].

A risk assessment tool developed to estimate a woman's risk of developing breast and/or ovarian cancer is the *Familial risk assessment – breast and ovarian cancer (FRA-BOC)* [43]. This is an on-line tool designed for use by health professionals with women not previously diagnosed with breast or ovarian cancer. It provides an estimation of the risk of developing breast or ovarian cancer, based on family history. The purpose of the tool is to identify women who should be referred to a family cancer clinic for further assessment and advice. In addition, it allows health professionals to reassure the majority of women who are at population risk, based on their family history.

## Extent of cancer among Aboriginal and Torres Strait Islander people

There are various ways to measure the extent of cancer in a given population, including prevalence, incidence, health service utilisation, mortality and burden of disease. This review focuses primarily on national data that provide an aggregate picture of the impact of cancer on Aboriginal and Torres Strait Islander people. The various measurements used in this review are defined below (see Measuring cancer). It should be noted however, that:

- the availability and quality of data varies
- there are data limitations associated with each of the measures
- cancer statistics for Aboriginal and Torres Strait Islander people are often underestimated.

As stated by the Australian Institute of Health and Welfare (AIHW), reliable national data on the diagnosis of cancer for Indigenous Australians are not available [2]. All state and territory cancer registries collect information on Indigenous status; however, in some jurisdictions the quality of Indigenous status data is insufficient for analyses. Information in the Australian Cancer Database on Indigenous



status is considered to be sufficiently complete for reporting for NSW, Vic, Qld, WA and the NT so data for these five jurisdictions were used to examine the incidence of cancer by Indigenous status. In this review, we are limited by the published data which often include only point estimates and rate ratios, often without confidence intervals. Where the difference between Aboriginal and Torres Strait Islander and non-Indigenous rates or rate ratios is small and confidence intervals are not provided, it is difficult to know whether the differences are real or subject to random variation. Appendix 1 provides a brief discussion of limitations associated with data sources used in this review.

### Measuring cancer

*Incidence* is the number of new primary cancers and not a recurrence of a previous primary cancer. Incidence is measured as an incidence rate for example, the number of new cases per 100,000 population per year.

*Prevalence* refers to the proportion of people alive who have been diagnosed with cancer. For example, the proportion of the population who have had cancer in the previous five years.

*Age-standardised rates* enable comparisons between populations that have different age structures. Age-standardisation is often used when comparing Aboriginal and Torres Strait Islander people and non-Indigenous people because the Aboriginal and Torres Strait Islander population has a younger age structure than the non-Indigenous population.

*Rate ratio (RR)* is the rate of Aboriginal and Torres Strait Islander people affected by cancer divided by the rate of non-Indigenous people affected by cancer.

*Ratio (R)* is the proportion of Aboriginal and Torres Strait Islander people affected by cancer divided by the proportion of non-Indigenous people affected by cancer.

*Burden of disease* provides a combined estimate of years of life lost due to premature mortality caused by cancer, and years of life lost due to disability or ill health caused by cancer. It is measured in disability-adjusted life years (DALYs).

*Fatal burden* refers to the burden of disease that is caused by premature mortality from cancer. It is measured in years of life lost (YLLs).

*Non-fatal burden* refers to the burden of disease that is caused by ill health due to cancer. It is measured in years lived with a disability (YLDs).

*Potentially avoidable deaths* are deaths among people aged less than 75 years from conditions (including cancer) considered potentially preventable and potentially treatable. Potentially avoidable deaths can be reduced through lifestyle improvements and appropriate primary prevention, early intervention and medical treatment.

*Survival* indicates the probability of a person being alive for a given period of time after being diagnosed with cancer.

## Combined cancers

### Incidence

For the period 2009–2013, there were 6,397, an average of 1,279 per year, Aboriginal and Torres Strait Islander people living in NSW, Vic, Qld, WA and the NT, diagnosed with cancer [2]. The age-specific incidence rate for all cancers combined increased with age for both Indigenous and non-Indigenous people. For 2013 after age-adjustment, the cancer incidence rate for all cancers combined was slightly higher for Aboriginal and Torres Strait Islander people compared with non-Indigenous people (500 per 100,000 and 423 per 100,000 respectively). For 2009–2013, incidence rates by state/territory ranged from 451 per 100,000 for NT to 565 per 100,000 for Vic.

For 2009–2013, lung cancer was the most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people followed by breast cancer (females), bowel cancer and prostate cancer (males) [2]. For the ten most commonly diagnosed cancers, age-standardised incidence rates were higher for Aboriginal and Torres Strait Islander people than non-Indigenous people for liver cancer (rate ratio 2.4); lung cancer (rate ratio 2.1); cancer of unknown primary sites (rate ratio 2.1); head and neck cancer (rate ratio 1.9); uterine cancer (rate ratio 1.8); and pancreatic cancer (rate ratio 1.6). After age-adjustment cancer incidence rates of Aboriginal and Torres Strait Islander people and non-Indigenous people for bowel cancer were equal (rate ratio 1.0). After age-adjustment the incidence rates for breast cancer (rate ratio 0.9); and prostate cancer (rate ratio 0.7) were lower for Aboriginal and Torres Strait Islander people than non-Indigenous people (Table 3).

**Table 3.** Age-standardised incidence rates for the 10 most commonly diagnosed cancers, by Indigenous status, NSW, Vic, Qld, WA and the NT, 2009–2013

Cancer type	Aboriginal and Torres Strait Islander	Non-Indigenous	Rate ratio
Lung	85	41	2.1
Breast (female)	99	112	0.9
Bowel	53	56	1.0
Prostate (male)	108	151	0.7
Head and neck	28	15	1.9
Uterine (female)	30	17	1.8
Liver	16	6	2.4
Unknown primary site	19	9	2.1
Pancreatic	17	11	1.6
Non-Hodgkin lymphoma	15	17	0.9

Notes:

1. Rates per 100,000 population, age-standardised to the Australian population at 30 June 2001
2. Cancers are ordered according to most commonly diagnosed cancers among Aboriginal and Torres Strait Islander people
3. Rate ratio Aboriginal and Torres Strait Islander: non-Indigenous people
4. Rounding may result in inconsistencies in calculated rate ratios

Source: AIHW, 2018 [2]

### Prevalence

The prevalence of cancer is the proportion of the population who have had cancer, often referred to as ‘people living with cancer’. This can be measured in two ways: from cancer registry data (information about all people diagnosed with cancer, based on clinical data about their cancer diagnosis); and information collected directly from people during population surveys.

Five year prevalence is the proportion of people currently alive who have been diagnosed with cancer in the previous five years, expressed as the number per 100,000 population. In 2013, it was estimated that 3,626 Aboriginal and Torres Strait Islander people currently alive had been diagnosed with cancer in the previous five years [2]. For Aboriginal and Torres Strait Islander people, the five-year prevalence rate was lower (590 per 100,000) than for non-Indigenous people (1,604 per 100,000). The lower five year prevalence rate for Aboriginal and Torres Strait Islander people may be due to lower survival rates and higher mortality rates compared with non-Indigenous people. Reflecting the higher incidence of cancer in males than females and in older age groups, cancer prevalence was higher for males than females and increased with increasing age for Aboriginal and Torres Strait Islander people as for non-Indigenous people. For females in the age group 65–69, the five-year prevalence was slightly higher for Aboriginal and Torres Strait Islander people compared with non-Indigenous people. The highest five year prevalence rates at the end of 2013 for Aboriginal and Torres Strait Islander people were for breast cancer (females) followed by prostate cancer (males), colorectal cancer and lung cancer, and for non-Indigenous people they were prostate cancer (males) followed by breast cancer (females), colorectal cancer and lung cancer.

For the ten most prevalent cancers in Aboriginal and Torres Strait Islander people to the end of 2007, the age-standardised five-year prevalence rates were higher for Aboriginal and Torres Strait Islander people than for non-Indigenous people for cancer of the cervix (rate ratio: 2.1) and cancers of the uterus (females) (rate ratio: 1.5) and lung (rate ratio: 1.5) [26]. Five-year prevalence rates were lower for Aboriginal and Torres Strait Islander people than for non-Indigenous people for melanoma of the skin (rate ratio: 0.9); thyroid cancer (rate ratio: 0.8); breast cancer (females) (rate ratio: 0.8); bowel cancer (rate ratio: 0.7); kidney cancer (rate ratio: 0.7); non-Hodgkin lymphoma (rate ratio: 0.6) and prostate cancer (rate ratio: 0.4) (Table 4).

**Table 4.** Five-year prevalence of the 10 most prevalent cancers in Aboriginal and Torres Strait Islander people by Indigenous status, NSW, Vic, Qld, WA and the NT, as at the end of 2007

Cancer type	Aboriginal and Torres Strait Islander	Non-Indigenous	Rate ratio
Breast (female)	166	220	0.8
Melanoma of the skin	115	128	0.9
Bowel	121	184	0.7
Prostate (male)	114	258	0.4
Lung	79	53	1.5
Uterus (female)	44	29	1.5
Thyroid	27	36	0.8
Cervix (female)	26	12	2.1
Non-Hodgkin lymphoma	31	53	0.6
Kidney	23	34	0.7

## Notes:

- 1 Rates per 100,000 population, age-standardised to the Australian population at 30 June 2001
- 2 Cancers are ordered according to most prevalent cancers among Aboriginal and Torres Strait Islander people
- 3 Rate ratio Aboriginal and Torres Strait Islander: non-Indigenous people
- 4 Rounding may result in inconsistencies in calculated rate ratios
- 5 Diagnosed with cancer in the previous five years (2003–2007)

Source: Derived from AIHW, 2013 [26]

Only limited information is available about self-reported cancer prevalence. The 2012–2013 AATSIHS asked participants if they had any ‘neoplasm’ (a benign or invasive tumour) for a duration of six months or more [30]. Self-reported prevalence (age-standardised) of any neoplasm was similar for Aboriginal and Torres Strait Islander people and non-Indigenous people (rate ratio 1.2), and similar for Aboriginal and Torres Strait Islander males and females.

## Survival

Information on survival from cancer for Aboriginal and Torres Strait Islander people is based on crude survival rates (observed survival) and is provided for states and territories where the data are considered of sufficient completeness for reporting [2]. Survival rates indicate that of the Aboriginal and Torres Strait Islander people living in NSW, Vic, Qld, WA and the NT who were diagnosed with cancer between 2007 and 2014, 50% had a chance of surviving five years after diagnosis. This compared with a relative survival rate of 65% for non-Indigenous people. The five year relative survival rates for Aboriginal and Torres Strait Islander males and females were considerably lower compared with non-Indigenous males and females (males: 46% compared with 64%, and females: 54% compared with 67%, respectively). The five-year survival for all cancers combined was highest for Aboriginal and Torres Strait Islander people 0–14 years and for non-Indigenous people 15–24 years and decreased with age for both populations.

**Table 5.** Five year relative survival for all cancers combined by Indigenous status and age, NSW, Vic, Qld, WA and the NT, 2007–2014

Age group (years)	Aboriginal and Torres Strait Islander	Non-Indigenous
0–14	82	84
15–24	78	87
25–44	66	84
45–64	50	74
65+	40	56

Source: AIHW, 2018 [2]

## Health service utilisation

Measures of health service utilisation give some indication of the uptake of health services by Aboriginal and Torres Strait Islander people and the extent to which they have access to these services. Included among these measures are figures for attendance at general practices and hospitals.

### General practice attendances

General practitioners (GPs) play a key role in cancer care. These roles can include diagnosis, referral to specialists, some treatments, psychological and practical support and transition to survivorship or palliative care. The Bettering the Evaluation and Care of Health (BEACH) survey, for which funding has now ceased, was a national, cross-sectional survey of the clinical activity of GPs [44]. The survey provides some evidence of the frequency with which GPs manage cancer problems for Aboriginal and Torres Strait Islander people.

In the period April 2010 to March 2015, around 0.7% of problems managed by GPs in encounters with Aboriginal and Torres Strait Islander people related to cancer [29]. This represented a rate of 12 per 1,000 encounters. After age-adjustment, GPs managed cancer problems during encounters with Aboriginal and Torres Strait Islander people at 0.8 times the rate of encounters with non-Indigenous patients (21 per 1,000 and 27 per 1,000 respectively). This suggests that Aboriginal and Torres Strait Islander people are less likely to visit a GP for cancer related matters than are non-Indigenous people.

### Hospitalisation

Hospital morbidity data for admitted patients provide information on hospital services required for cancer including diagnosis, procedures and treatment. In any given year, the number of people admitted to hospital for cancer reflects not only the number of people with cancer (prevalence) but the number of cancer related health needs requiring admission. Despite limitations, hospitalisation data remains the most comprehensive source of information about health service utilisation.

In 2016–17, there were 7,931 hospital separations for neoplasms<sup>1</sup> for Aboriginal and Torres Strait Islander people in Australia [45]. After age-adjustment, Aboriginal and Torres Strait Islander people were less likely to be hospitalised for neoplasms than non-Indigenous people (19 per 1,000 and 25 per 1,000 respectively).

For 2013–15 in Australia, Aboriginal and Torres Strait Islander people tended to have lower hospitalisation rates than non-Indigenous people for a principal diagnosis of cancer (12 per 1,000 and 16 per 1,000 respectively) [29]. Aboriginal and Torres Strait Islander males experienced a higher hospitalisation rate for a principal diagnosis of cancer (14 per 1,000) than females (11 per 1,000). This pattern was also evident for non-Indigenous people with males hospitalised at a higher rate (19 per 1,000) than females (13 per 1,000).

Age-specific hospitalisation rates for cancer increased with age for both Aboriginal and Torres Strait Islander people and non-Indigenous people between July 2013 and June 2015 [29]. The rates are relatively stable up until 34 years of age. However, after this age the rates increase substantially for both populations with the highest rate being in the 65 years and over age group at 49 per 1,000 for Aboriginal and Torres Strait Islander people and 72 per 1,000 for non-Indigenous people (Table 6).

<sup>1</sup> Neoplasms C00-D48 also includes benign neoplasms D10-D36 ICD-10-AM.

**Table 6. Age-specific hospitalisation rates for a principal diagnosis of cancer, by Indigenous status and sex, all jurisdictions, July 2013–June 2015**

Age group (yrs)	Males			Females			Total		
	Aboriginal and Torres Strait Islander	Non-Indigenous	Rate ratio	Aboriginal and Torres Strait Islander	Non-Indigenous	Rate ratio	Aboriginal and Torres Strait Islander	Non-Indigenous	Rate ratio
0–4	1.4	2.5	0.6	1.5	2.2	0.7	1.5	2.3	0.6
5–14	0.9	1.5	0.6	1.0	1.2	0.9	1.0	1.4	0.7
15–24	1.1	1.4	0.8	0.8	1.0	0.7	0.9	1.2	0.7
25–34	1.1	1.9	0.6	2.0	2.3	0.9	1.5	2.1	0.7
35–44	3.5	4.5	0.8	5.5	6.5	0.8	4.5	5.5	0.8
45–54	12	13	0.9	12	15	0.8	12	14	0.9
55–64	29	37	0.8	23	26	0.9	26	31	0.8
65+	57	94	0.6	42	53	0.8	49	72	0.7
<b>All ages</b>	<b>14</b>	<b>19</b>	<b>0.7</b>	<b>11</b>	<b>13</b>	<b>0.8</b>	<b>12</b>	<b>16</b>	<b>0.8</b>

- Notes:
- 1 Rates per 1,000 population, directly age-standardised using the Australian 2001 standard population
  - 2 Based on the ICD-10-AM seventh edition codes C00-C97, D45, D46, D47.1, D47.3, D47.4 and D47.5
  - 3 Rates are calculated based on the 2011 Census
  - 4 Data includes public and private hospitals in all jurisdictions, and exclude private hospitals in the NT
  - 5 Rate ratio Aboriginal and Torres Strait Islander: non-Indigenous people
  - 6 Rounding may result in inconsistencies in calculated ratios

Source: AIHW, 2017 (derived from Table 1.08.11) [29]

Between July 2013 and June 2015, the hospitalisation rate for a principal diagnosis of cancer was lower for Aboriginal and Torres Strait Islander people compared with non-Indigenous people in all remoteness classifications (Table 7) [29].

**Table 7. Age-standardised hospitalisation rates for a principal diagnosis of cancer, by Indigenous status and remoteness, all jurisdictions, July 2013–June 2015**

Remoteness area	Aboriginal and Torres Strait Islander	Non-Indigenous	Rate ratio
Major cities	12	16	0.8
Inner regional	13	16	0.8
Outer regional	12	16	0.7
Remote	11	15	0.7
Very remote	9.5	14	0.7
<b>Total</b>	<b>12</b>	<b>16</b>	<b>0.8</b>

- Notes:
- 1 Rates per 1,000 population, directly age-standardised using the Australian 2001 standard population
  - 2 Data for public and private hospitals in all jurisdictions
  - 3 Based on the ICD-10-AM seventh edition codes C00-C97, D45, D46, D47.1, D47.3, D47.4 and D47.5
  - 4 Rate ratio Aboriginal and Torres Strait Islander: non-Indigenous people

Source: AIHW, 2017 (derived from Table 1.08.13) [29]

Even though Aboriginal and Torres Strait Islander people have lower hospitalisation rates for cancer compared with non-Indigenous people, their average length of stay in hospital is longer. For 2006–07 to 2010–11, Aboriginal and Torres Strait Islanders living in NSW, Vic, Qld, WA, SA and NT experienced longer age-standardised average length of stay<sup>2</sup> in hospital compared with non-Indigenous people (9.6 and 7.7 days respectively) [26]. This may be partly explained by increased difficulties they experience in accessing appropriate health services and issues related to need for travel to access treatment.

Endocrine, nutritional and metabolic diseases was the most common category of additional diagnoses for Aboriginal and Torres Strait Islander people who were admitted to hospital with a principal diagnosis of cancer and was present in 22% of cancer admissions for

<sup>2</sup> Average length of stay does not include day admissions only overnight hospitalisations [26]

2006–07 to 2010–11 for Aboriginal and Torres Strait Islanders living in NSW, Vic, Qld, WA, SA and NT [26]. This was followed by diseases of the circulatory system (17%). Age-standardised rates revealed that Aboriginal and Torres Strait Islander people who were hospitalised with a principal diagnosis of cancer had an additional diagnosis of mental and behavioural disorders at 1.5 times the rate of non-Indigenous people and an additional diagnosis of endocrine, nutritional and metabolic diseases and diseases of the respiratory system at 1.4 times the rate for non-Indigenous people.

For specific cancers where details are available in 2014–15, the age-standardised hospitalisation rate for lung cancer in Australia for Aboriginal and Torres Strait Islander people was 2.0 times higher than for non-Indigenous people (1.3 per 1,000 and 0.7 per 1,000 respectively) [46]. For cervical cancer, the age-standardised hospitalisation rate for Aboriginal and Torres Strait Islander females was 3.0 times higher than for non-Indigenous people (0.2 per 1,000 and 0.07 per 1,000).

More details are available for the period 2006–07 to 2010–11, Aboriginal and Torres Strait Islander people were more likely to be hospitalised for the following cancers than non-Indigenous people: cervical cancer (rate ratio: 3.0); liver cancer (rate ratio 2.1); and lung cancer (rate ratio 1.6) [26]. Aboriginal and Torres Strait Islanders were less likely than non-Indigenous people to be hospitalised for non-melanoma of the skin (rate ratio 0.3); non-Hodgkin lymphoma (rate ratio 0.4); prostate cancer (rate ratio 0.4); bowel cancer (rate ratio 0.6) and acute lymphoblastic leukaemia (rate ratio 0.6); breast cancer (female) (rate ratio 0.7) and cancer of a secondary site (rate ratio 0.9) (Table 8).

**Table 8. Age-standardised hospitalisation rates of the 10 most common principal diagnoses of cancer, by Indigenous status, NSW, Vic, Qld, WA, SA and public hospitals in the NT, 2006–07 to 2010–11**

Primary cancer	Aboriginal and Torres Strait Islander	Non-Indigenous	Rate ratio
Secondary site	14	17	0.9
Lung	12	7.9	1.6
Breast (female)	14	20	0.7
Bowel	7.8	13	0.6
Non-melanoma of skin	9.7	37	0.3
Non-Hodgkin lymphoma	3.3	8.4	0.4
Prostate (male)	12	29	0.4
Acute lymphoblastic leukaemia	1.1	2.0	0.6
Cervical (female)	4.8	1.6	3.0
Liver	3.1	1.5	2.1

- Notes:
- 1 Rates per 10,000 population, age-standardised to the Australian population at 30 June 2001
  - 2 Cancers are ordered according to most common principal diagnosis of cancer among Aboriginal and Torres Strait Islander people
  - 3 Rate ratio Aboriginal and Torres Strait Islander: non-Indigenous people
  - 4 Hospitalisations in which the principal diagnosis is cancer ICD-10-AM codes C00-C97, D45, D46, D47.1 and D47.3
  - 5 Rounding may result in inconsistencies in calculated ratios

Source: Derived from AIHW, 2013 [26]

## Mortality

For 2011–2015, 2,754 Aboriginal and Torres Strait Islander people from NSW, Qld, WA, SA and the NT died from cancer, an average of 551 deaths per year [2]. Between 1998 and 2015, the age-standardised mortality rate for all cancers combined ranged from 195 per 100,000 to 246 per 100,000 for Aboriginal and Torres Strait Islander people whereas for non-Indigenous people, the rate decreased from 194 per 100,000 to 164 per 100,000.

In 2011–2015, the age-specific mortality rates from cancer were higher for Aboriginal and Torres Strait Islander people aged between 35–85+ years, compared with non-Indigenous people [2].

In 2016, cancers of the trachea, bronchus and lung combined were the fourth leading cause of death for Aboriginal and Torres Strait Islander people (184 deaths: 107 males and 77 females) living in NSW, Qld, WA, SA and the NT, with the overall age-standardised death rate 2.1 times higher than for non-Indigenous people [47].

In terms of the ten leading causes of cancer deaths for the period 2011–2015 in NSW, Qld, WA, SA and the NT, the age-standardised mortality rates were higher for Aboriginal and Torres Strait Islander people than for non-Indigenous people for cancers of the head and neck (rate



ratio: 3.4); liver (rate ratio: 2.4); lung (rate ratio: 1.8); stomach (rate ratio: 1.8); oesophagus (rate ratio: 1.8); unknown primary sites (rate ratio: 1.8) and pancreas (rate ratio: 1.2) [2]. Cancer mortality rates were lower for Aboriginal and Torres Strait Islander people than non-Indigenous people for bowel cancer (rate ratio: 0.9) and prostate cancer (rate ratio 0.9) (Table 9) [2].

**Table 9. Age-standardised hospitalisation rates of the 10 most common principal diagnoses of cancer, by Indigenous status, NSW, Vic, Qld, WA, SA and public hospitals in the NT, 2006–07 to 2010–11**

Cancer type	Aboriginal and Torres Strait Islander	Non-Indigenous	Rate ratio
Lung	57	31	1.8
Liver	15	6	2.4
Head and neck	14	4	3.4
Unknown primary site	18	10	1.8
Breast (female)	24	20	1.2
Bowel	14	15	0.9
Pancreas	12	10	1.2
Oesophagus	8.5	4.6	1.8
Stomach	7.4	4.2	1.8
Prostate (male)	24	27	0.9

Notes:

1. Rates per 100,000 population, age-standardised to the Australian population at 30 June 2001
2. Cancers are ordered according to most common causes of cancer deaths among Aboriginal and Torres Strait Islander people
3. Rate ratio Aboriginal and Torres Strait Islander: non-Indigenous people
4. Rounding may result in inconsistencies in calculated ratios

Source: AIHW, 2018 (derived from age-standardised mortality graphs) [2]

For 2011–2015, the age-standardised mortality rate for all cancers combined ranged from 159 per 100,000 (major cities) to 246 per 100,000 (remote Australia) across remoteness areas for Aboriginal and Torres Strait Islander people; for non-Indigenous people, it ranged from 118 per 100,000 (very remote Australia) to 139 per 100,000 (outer regional Australia) [2].

## Burden of disease

Cancer was the third most common contributor to fatal burden (17%) for Aboriginal and Torres Strait Islander people for 2011 [48]. Cancer contributed a higher proportion of years of life lost (YLL) for Aboriginal and Torres Strait Islander females ranking first (20%), compared with males ranking third (16%). For Aboriginal and Torres Strait Islander people aged 45–64 years, cancer was the second highest contributor to fatal burden at 27%. Lung cancer comprised the largest proportion of the fatal burden due to cancer (14%).

## Potentially avoidable deaths

For 2008–2012, in NSW, Qld, WA, SA and the NT, cancer<sup>3</sup> was ranked second at 18% in terms of conditions causing avoidable mortality for Aboriginal and Torres Strait Islander people [49]. Lung cancer was the highest individual contributor, comprising 7% of the total 18%. After age-adjustment, cancer as a cause of avoidable mortality among Aboriginal and Torres Strait Islander people was 1.7 times the rate for non-Indigenous people (97 per 100,000 compared with 55 per 100,000). After age-adjustment, cancer was ranked third (14%)<sup>4</sup> in terms of conditions that contributed to the avoidable mortality gap between Aboriginal and Torres Strait Islander people and non-Indigenous people.

## Burden of disease (non-fatal)

In 2011, cancer comprised 0.5% of the total figure for non-fatal burden of disease among Aboriginal and Torres Strait Islander people [48]. Cancer burden was almost entirely due to dying prematurely; living with cancer only accounted for 2.7% of the total burden caused by cancer. Aboriginal and Torres Strait Islander males experienced more non-fatal burden due to cancer than Aboriginal and Torres Strait Islander females (rate ratio of 1.1). In terms of specific cancers, the non-fatal burden caused by breast cancer was the highest at 6.4% of the overall burden for that disease.

<sup>3</sup> For the purposes of potentially avoidable deaths ICD-10 for cancer includes skin, breast (females), cervix, prostate (males), kidney, thyroid, Hodgkin's disease and acute lymphoid leukaemia/acute lymphoblastic leukaemia.

<sup>4</sup> Ischaemic heart disease contributed the largest proportion to the avoidable mortality gap (22%) and diabetes the second largest (17%) [49].

## Specific cancers

### Lung

For 2009–2013, lung cancer was the most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people living in NSW, Vic, Qld, WA and the NT with 945 new cases of lung cancer, an average of 189 cases per year [2]. The age-standardised incidence rate was 2.1 times higher for Aboriginal and Torres Strait Islander people (85 per 100,000) than for non-Indigenous people (41 per 100,000). The lung cancer incidence rate for males was 1.4 times higher (103 per 100,000) than for females (72 per 100,000). New cases of lung cancer increased with age for the Aboriginal and Torres Strait Islander population with the highest incidence rate being for the 65 years and over age group at 448 new cases per 100,000 population. WA recorded the lowest lung cancer incidence rate for Aboriginal and Torres Strait Islander people (70 new cases per 100,000), followed by Vic (78 per 100,000), the NT (78 per 100,000), Qld (89 per 100,000) and NSW (92 per 100,000). Prevalence rates for lung cancer were also higher for Aboriginal and Torres Strait Islander people at the end of 2013 than they were for non-Indigenous people [2]. Prevalence rates increased with increasing age up to 75–79 years and then decreased for both populations.

In 2014–15, the age-standardised hospitalisation rate for lung cancer in Australia for Aboriginal and Torres Strait Islander people was 2.0 times higher than for non-Indigenous people (1.3 per 1,000 and 0.7 per 1,000 respectively) [46]. Hospitalisation rates for lung cancer were slightly higher for Aboriginal and Torres Strait Islander males than females (1.4 per 1,000 and 1.3 per 1,000 respectively), and also higher for non-Indigenous males than females (0.8 per 1,000 and 0.5 per 1,000 respectively).

For 2007–2014, the five-year relative survival for Aboriginal and Torres Strait Islanders diagnosed with lung cancer was 11% on average compared with their counterparts in the Indigenous population [2]. Non-Indigenous people diagnosed with lung cancer had a 16% chance on average of surviving five years compared with their counterparts in the non-Indigenous population.

In 2016, cancers of the trachea, bronchus and lung combined were the fourth leading cause of death for Aboriginal and Torres Strait Islander people (184 deaths: 107 males and 77 females) living in NSW, Qld, WA, SA and the NT, with the overall age-standardised death rate 2.1 times higher than for non-Indigenous people [47].

Lung cancer was the leading cause of cancer deaths among Aboriginal and Torres Strait Islander people between 2011 and 2015 with 705 deaths, an average of 141 deaths per year [2]. The age-standardised mortality rate for lung cancer was 1.8 times higher for Aboriginal and Torres Strait Islander people (57 per 100,000) than for non-Indigenous people (31 per 100,000).

### Breast

Breast cancer was the second most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people living in NSW, Vic, Qld, WA and the NT during 2009–2013: there were 771 new cases of breast cancer (females), an average of 154 cases per year [2]. During this period, the age-standardised incidence rate was lower (rate ratio 0.9) for Aboriginal and Torres Strait Islander people than non-Indigenous people (99 per 100,000 and 112 per 100,000 respectively). At the end of 2013 for Aboriginal and Torres Strait Islander people, the highest five year prevalence rate for cancer was for breast cancer (females) [2].

For 2013–2015, there were 515 Aboriginal and Torres Strait Islander females hospitalised in Australia for breast cancer (1.3 per 1,000 after age-standardisation) [29]. Aboriginal and Torres Strait Islander women were less likely to be hospitalised with breast cancer than non-Indigenous females (rate ratio 0.7).

For 2007–2014, the five-year relative survival for Aboriginal and Torres Strait Islanders diagnosed with breast cancer was 81% on average compared with their counterparts in the Indigenous population [2]. Non-Indigenous people diagnosed with breast cancer had a 90% chance on average of surviving five years compared with their counterparts in the non-Indigenous population. The five-year relative survival was lowest for the 25–44 year age group for Aboriginal and Torres Strait Islander women and increased with age. For non-Indigenous women, five-year relative survival was similar for 15–24 and 45–64 years and decreased for 65 years and older.

For 2011–2015, 171 Aboriginal and Torres Strait Islander females died from breast cancer, an average of 34 deaths per year [2]. After age-standardisation, there were 24 deaths per 100,000 for Aboriginal and Torres Strait Islander people compared with 20 per 100,000 for non-Indigenous people (rate ratio: 1.2).

The poorer outcomes for Aboriginal and Torres Strait Islander people suggest that breast cancers are diagnosed at a later stage when treatment is not as effective [26, 50].

## Bowel

For 2009–2013, bowel cancer was the third most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people living in NSW, Vic, Qld, WA and the NT; there were 612 new cases, an average of 122 cases per year [2]. Incidence rates were similar for Aboriginal and Torres Strait Islander people and non-Indigenous people (53 per 100,000 and 56 per 100,000 respectively). Aboriginal and Torres Strait Islander males had a bowel cancer incidence rate 1.4 times higher than for females (65 per 100,000 and 45 per 100,000 respectively). New cases of bowel cancer increased with age for the Aboriginal and Torres Strait Islander and non-Indigenous populations with the highest incidence rates being for the 65 years and over age group (243 per 100,000 and 296 per 100,000 respectively) [2]. Five-year prevalence rates at the end of 2007 were lower for Aboriginal and Torres Strait Islander people than for non-Indigenous people (rate ratio 0.7) [26].

Aboriginal and Torres Strait Islander people were less likely than non-Indigenous people to be hospitalised with bowel cancer (rate ratio 0.6) in NSW, Vic, Qld, WA, SA and NT for 2006-07 to 2010-11 [26].

For 2007–2014, Aboriginal and Torres Strait Islander people diagnosed with bowel cancer had a 58% chance on average of surviving five years compared with their counterparts in the Indigenous population [2]. Non-Indigenous people diagnosed with bowel cancer had a 67% chance on average of surviving five years compared with their counterparts in the non-Indigenous population.

For 2011–2015, Aboriginal and Torres Strait Islander people had a slightly lower age-standardised bowel cancer mortality rate than non-Indigenous people (14 per 100,000 compared with 15 per 100,000) [2].

Factors which may explain the similar incidence and lower mortality rates for bowel cancer include a reluctance to seek medical care for symptoms [51] and diagnosis at a later stage when the primary site of the cancer is no longer evident [50]. Estimated incidence and mortality rates for bowel cancer may not fully reflect the extent of the disease among Aboriginal and Torres Strait Islander people [52-54].

## Prostate

For 2009–2013, prostate cancer was the fourth most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people living in NSW, Vic, Qld, WA and the NT: there were 526 new cases, an average of 105 cases per year [2]. The age-standardised incidence rate was lower (rate ratio 0.7) for Aboriginal and Torres Strait Islander males than for non-Indigenous males (108 per 100,000 and 151 per 100,000 respectively). Five-year prevalence rates, as at the end of 2007, were lower for Aboriginal and Torres Strait Islander males than for non-Indigenous males (rate ratio 0.4) [26].

Aboriginal and Torres Strait Islander males were less likely to be hospitalised with prostate cancer than non-Indigenous males (rate ratio 0.4) in NSW, Vic, Qld, WA, SA and NT in 2006-07 to 2010-11 [26].

For 2007–2014 Aboriginal and Torres Strait Islander people diagnosed with prostate cancer had an 86% chance on average of surviving five years compared with their counterparts in the Indigenous population [2]. Non-Indigenous people diagnosed with prostate cancer had a 92% chance on average of surviving five years compared with their counterparts in the non-Indigenous population.

For 2011–2015, Aboriginal and Torres Strait Islander people had a slightly lower (rate ratio: 0.9) age-standardised prostate cancer mortality rate than non-Indigenous people (24 per 100,000 and 27 per 100,000 respectively) [2].

## Cervical

Cervical cancer (females) diagnosis information is sourced from pathology forms which currently do not record information on Indigenous status in most states and territories [39]. This means that reliable national data on the incidence of cancer for Aboriginal and Torres Strait Islander people are not available. Only data from NSW, Vic, Qld, WA and the NT are considered of sufficient quality and are used to examine the incidence of cervical cancer by Indigenous status.

For 2009–2013, there were 150 new cases of cervical cancer diagnosed among Aboriginal and Torres Strait Islander people living in NSW, Vic, Qld, WA and the NT, an average of 30 cases per year [2]. Cervical cancer incidence in Aboriginal and Torres Strait Islander people was higher than for non-Indigenous people (16 per 100,000 and 6.3 per 100,000 respectively). Five-year prevalence rates as at the end of 2007, were also higher for Aboriginal and Torres Strait Islander females than for non-Indigenous females (rate ratio 2.1) [26].

For 2014–15, the age-standardised hospitalisation rate in Australia for cervical cancer for Aboriginal and Torres Strait Islander females was 3.0 times higher than for non-Indigenous females (0.2 per 1,000 and 0.07 per 1,000 respectively) [46].

For 2007–2014, Aboriginal and Torres Strait Islander women diagnosed with cervical cancer had a 56% chance on average of surviving for five years compared with their counterparts in the Indigenous population [2]. Non-Indigenous women diagnosed with cervical cancer had a 72% chance on average of surviving for five years compared with their counterparts in the non-Indigenous population.

For 2011–2015, 56 Aboriginal and Torres Strait Islander women died from cervical cancer in, NSW, Vic, Qld, WA and the NT, an average of 11 deaths per year [2]. Age-standardised mortality from cervical cancer was 3.9 times higher for Aboriginal and Torres Strait Islander people than for non-Indigenous people (6.6 per 100,000 and 1.7 per 100,000 respectively).

Later stage at diagnosis and availability of treatment, especially for women in remote areas, are suggested to be factors accounting for the higher cervical cancer incidence and mortality rates found for Aboriginal and Torres Strait Islander women [39].

## Prevention and management

The prevention and management of cancer is vital to the current and future health of Aboriginal and Torres Strait Islander people. It is generally accepted that for cancer prevention and management programs to be effective they require evidence based health promotion measures, public health interventions and clinical services [55]. It is important that programs for Aboriginal and Torres Strait Islander people are delivered sensitively, tailored to community needs, and implemented collaboratively [56, 57]. It is also recommended that such programs are developed in a broader context that incorporates the social determinants of health and acknowledges the impact of factors, such as poverty, culture, racism, employment and education on Aboriginal and Torres Strait Islander health [6].

## Prevention

Primary prevention is designed to improve or protect the health of high risk individuals and includes public policy interventions, such as the plain packaging of cigarettes, information to support healthy lifestyles, such as physical activity and healthy diet and limited intake of alcohol, and mass media campaigns, such as quitting smoking and using sunscreens. It also includes empowering individuals, strengthening community capacity and addressing determinants of health [29]. The prevention of cancer, particularly in high risk individuals, is a key objective of many of these activities.

As described earlier, Aboriginal and Torres Strait Islander people overall have more behavioural risk factors which are known to increase the risk of developing cancer [26]. Primary prevention can prevent or delay the development of cancer in high risk individuals by:

- identifying those at high risk through the use of risk assessment tools
- delivering education programs
- promoting lifestyle modifications that focus on healthy living.

Health promotion and education have been identified as important mechanisms to help address factors impacting the health of people and communities [58]. It is recommended that health promotion and education approaches recognise and appreciate the importance of local cultures and have an emphasis on capacity building, community empowerment and local ownership. It is important that approaches to Aboriginal and Torres Strait Islander health promotion and education are appropriate, respectful, collaborative and locally suitable [57].

## Education

There is a range of information and resources which are aimed at educating Aboriginal and Torres Strait Islander people about cancer, including those produced by Cancer Council Australia [59]. Some, such as workshop materials and handbooks, are aimed at health professionals to provide them with the tools necessary to inform and support their clients. Materials made directly available to consumers include flyers, DVDs and guides on how common cancers are detected and treated and, on living with cancer. Information is also produced at a jurisdictional level by Cancer Council Australia's affiliate organisations.

One such resource was a flipchart produced by Cancer Council WA and the Western Australian Cancer and Palliative Care Network. This was intended for use by health professionals to raise awareness among Aboriginal and Torres Strait Islander people about bowel cancer and bowel cancer screening in a culturally relevant way. A study was later commissioned to evaluate the flipchart. This evaluation found that although the resource was highly acclaimed, it had been under-utilised and recommended that additional resources be produced in order to increase screening uptake in the Aboriginal community [60]. As a result, a DVD entitled *Making time for bowel cancer screening* was developed and a subsequent evaluation of the implementation and use of this resource commissioned [61]. Once again, while the resource was found to have been well received, there was low utilisation of the DVD [62]. More recently, Cancer Council WA have produced the *Aboriginal Cancer education video* which aims to increase knowledge about the importance of cancer prevention, screening, early detection and various treatment options and support services [63].

Evaluations demonstrate that possessing a health education tool, even if it is of good quality, does not ensure that the resource will be used by health professionals [64]. Health professionals regularly receive materials but the capacity and resources of practitioners, particularly

those working in Aboriginal and Torres Strait Islander primary health care services, to utilise such resources in the context of other demands, is particularly limited [58]. This highlights the importance of evaluating health promotion tools to ensure they are being used to contribute to Aboriginal and Torres Strait Islander health outcomes and reduce the health disparities that currently exist [65]. Despite the acknowledged benefits and importance of evaluating how these tools have been used, only a small number of evaluations of Aboriginal and Torres Strait Islander health promotion tools have been undertaken to date.

## Lifestyle modifications

Alcohol consumption, smoking, poor nutrition, being overweight or obese are known to increase the risk of developing cancer [5]. Culturally appropriate, locally supported, targeted intensive lifestyle programs are recommended for Aboriginal and Torres Strait Islander people to provide participants with the life skills, knowledge and support needed to make sustainable lifestyle changes to prevent the onset of cancer. Healthy lifestyle programs must be considered in a broader context that incorporates the social determinants of health, and population-based approaches to health improvement. This approach recognises that the risk of developing chronic disease is not only directly influenced by an individual's behaviours but also by cultural, historical, social, geographical, economic and community factors, and government health policies and services [6].

Reviews of healthy lifestyle programs addressing smoking, physical activity and nutrition among Aboriginal and Torres Strait Islander people found that programs can have positive health effects [6, 66]. Although there is limited evidence for long-term behavioural change following health promotion interventions, a small study of urban Aboriginal and Torres Strait Islander young people found some change in knowledge and attitudes following health promotion interventions in school [67]. At the heart of health promotion is effective communication that takes into account language and world view to support people to live healthy lives [68]. Initiatives are more likely to be effective if they are initiated and managed by the community, with technical (and sometimes financial) support being provided by external organisations [6].

In 2014–15, all Commonwealth funded Aboriginal and Torres Strait Islander primary health care services offered health promotion/education programmes aimed at lifestyle modifications [68]. Many of these offered healthy lifestyle programs (81%) and alcohol use treatment/prevention awareness programs (40%). They also offered a range of health promotion activities, such as physical activity/healthy weight activity (73%) and living skills such as cooking and nutrition) (61%).

Lifestyle modification programs have been implemented at a local level by the Regional Tackling Smoking Healthy Lifestyle Teams. These were established as part of the Tackling Indigenous Smoking program, a component of the Australian government's Indigenous Australians' Health Programme [69]. The regional teams work to raise awareness of the health impacts of tobacco smoking and chronic disease in Aboriginal and Torres Strait Islander communities, to actively promote positive lifestyle changes and to assist timely access to appropriate health services as needed. In WA, Tackling Smoking – a development of the Midwest Region Wide Tobacco Strategy and Campaign implemented a multi-faceted promotional campaign using radio, newspaper, community events and the distribution of promotional materials. Results from a short-term evaluation indicated early success and an increase in calls to the Aboriginal Quitline following the campaign [68].

Broader initiatives that extend beyond the immediate scope of the health sector have also been proposed to encourage healthier lifestyles and therefore help reduce cancer in the Aboriginal and Torres Strait Islander population. They include [70]:

- increasing availability of and access to healthy foods (e.g. in stores and through community gardens and traditional food projects)
- limiting advertising of alcohol and tobacco products
- using taxation as a lever to increase the price of alcohol and tobacco
- encouraging physical activity through partnerships with local councils
- providing clearer food labelling and education regarding the nutritional value of foods, such as the Health Star Rating social marketing campaign which includes a specific focus on out-of-home and social media aimed at Aboriginal and Torres Strait Islander audiences [68].

## Management

Providing appropriate, effective cancer management for Aboriginal and Torres Strait Islander people depends on: access to a broad range of health services that meet the needs of Aboriginal and Torres Strait Islander patients [56, 71, 72]; and coordinated interaction between patients, healthcare providers and the healthcare system [73, 74].

Recommendations for improving cancer management for Aboriginal and Torres Strait Islander people include:

- early detection of cancer
- availability of good quality primary and tertiary health care
- access to health care services including specialist cancer services.

## Health care

Mainstream (including specialist cancer services) and community controlled primary health care services in Australia play a critical role in the delivery of cancer care at a local level. To meet the needs of Aboriginal and Torres Strait Islander people, primary health care services have to deliver care that is both competent and culturally appropriate [75]. Culture and identity are central to Aboriginal and Torres Strait Islander perceptions of health, which encompass both the physical wellbeing of the individual, and the social, emotional and cultural the wellbeing of the community. Services that deliver primary health care to Aboriginal and Torres Strait Islander people must recognise the importance of community values, such as connection to culture, family and land, and opportunities for self-determination. Primary health care services that are flexible in their delivery of services for Aboriginal and Torres Strait Islander people to incorporate cultural protocols, allowing a social view of health and making the service more welcoming, have the potential to improve Aboriginal and Torres Strait Islander health and wellbeing [76].

Providing cancer services that meet the needs of Aboriginal and Torres Strait Islander patients is a critical element in improving outcomes [71]. The National Aboriginal and Torres Strait Islander Cancer Framework (the *Framework*) has identified that 'culturally safe services and a culturally competent workforce... are core requirements for improving cancer outcomes' [56], highlighting the essential role cancer service providers have in encouraging and maintaining Aboriginal and Torres Strait Islander people's attendance at cancer services. Culturally appropriate cancer care is based upon a strong therapeutic relationship between patients and tertiary and primary health professionals [73, 74] which requires cross-cultural knowledge and expert skills on the part of health professionals [74]. It is recommended that cultural competence training is made available to all staff members to help improve communication and quality of care provided [77, 78] and to ensure that Aboriginal and Torres Strait Islander people are not discouraged from presenting [79]. Health care providers who understand the beliefs and perspectives of Aboriginal and Torres Strait Islanders regarding cancer [20, 80] will be better placed to build an appropriate therapeutic relationship in cancer-related consultations.

A number of cultural awareness training initiatives have been introduced which aim to enhance the understanding of primary care health professionals about the needs of their Aboriginal and Torres Strait Islander clients. One study of such an initiative in regional Victoria found that Aboriginal clients reported the difference that cultural training for BreastScreen staff had made and felt genuinely welcomed by clinic staff [81]. Others studies reported similarly successful initiatives which resulted in increased numbers of Aboriginal women participating in breast screening programs [82, 83].

Aboriginal and Torres Strait Islander Health Workers have been identified as being particularly important in the delivery of effective and culturally safe health care to Aboriginal and Torres Strait Islander patients [84-87]. The *Framework* makes it clear that improved availability of Aboriginal and Torres Strait Islander Health Workers, with both community knowledge and clinical knowledge, is an important enabler in providing high quality care for Aboriginal and Torres Strait Islander people with cancer [56]. Numerous studies have highlighted the many practical benefits of having Aboriginal and Torres Strait Islander health professionals who can provide culturally safe health care to Aboriginal and Torres Strait Islander patients and educate other health professionals on the delivery of culturally appropriate care [84, 86-88]. In a study of Aboriginal and Torres Strait Islander cancer patients receiving treatment at four major Qld public hospitals, the Indigenous Health Liaison Officers were the most commonly used of all hospital services available, highlighting the importance of their role in supporting Aboriginal and Torres Strait Islander cancer patients [89].

Aboriginal and Torres Strait Islander Community Controlled Health Services play an important role in delivering essential primary health care service to Aboriginal and Torres Strait Islander people in a culturally secure manner [29]. Health services run by Aboriginal and Torres Strait Islander communities provide holistic care that is relevant to their local community and reflects the Aboriginal view of health which addresses not just the physical wellbeing of an individual but the social, emotional and cultural wellbeing of the whole community [90]. Such services can deliver effective prevention and management programs that enable lifestyle changes that are maintained and supported by the community.



### Aboriginal and Torres Strait Islander Community Controlled Health Services

Aboriginal and Torres Strait Islander Community Controlled Health Services are located in all jurisdictions and are funded by the federal, state and territory governments and other sources [91]. They are planned and governed by local Aboriginal and Torres Strait and Torres Strait Islander communities and aim to deliver holistic and culturally appropriate health and health-related services. Services vary in the primary health care activities they offer. Possible activities include: diagnosis and treatment of illness or disease; management of chronic illness; transportation to medical appointments; outreach clinic services; immunisations; dental services; and dialysis services.

Aboriginal and Torres Strait Islander cancer support groups have been identified as important for improving cancer awareness and increasing participation in cancer screening services [92]. Aboriginal women attending these support groups have reported an increased understanding of screening and reported less fear and concern over cultural appropriateness, with increases in screening rates [19]. Support groups have also been found to help in follow up and ongoing care for cancer survivors [19, 93], particularly where they are shaped to meet the needs of Aboriginal and Torres Strait Islander people [73, 94].

In recognition of their specific care requirements, a tool has been developed to assess the unmet supportive care needs of Aboriginal and Torres Strait Islander patients diagnosed with cancer – the *Supportive care needs assessment tool for Indigenous people (SCNAT-IP)*. These needs include specific information, psychological counselling, assistance with travel to tertiary treatment and financial assistance. The tool was used in a study based in Qld which assessed cancer patients' needs within three months and at six months post-diagnosis. It found that as supportive care needs change over time, they should be monitored throughout the patient's cancer journey [95].

In addition to high quality primary health care, which is key to early diagnosis and linkage to cancer service pathways [79], effective cancer management requires affordable and timely access to tertiary specialist services for treatment. Several studies have shown poorer survival rates for cancer among Aboriginal and Torres Strait Islander people [27, 96-98]. A study of lung cancer patients in Qld found that most of the survival deficit could be explained by a disparity in treatment [99]. Not only are Aboriginal and Torres Strait Islander people less likely to have treatment for cancer (surgery, chemotherapy and radiotherapy), they also tend to wait longer for surgery [69]. It is suggested that appropriate access to tertiary services may be facilitated through investment in Telehealth [79, 100].

Models of care that promote integration between the primary and tertiary care settings are recommended for all patients with cancer [101]. Gaps in diagnosis, treatment and survival between Aboriginal and Torres Strait Islander people and non-Indigenous people indicate that current programs and models of service delivery often do not adequately meet the needs of Aboriginal and Torres Strait Islander people with cancer [79]. Improved links between Aboriginal and Torres Strait Islander communities, primary health care providers and mainstream cancer care services could improve Aboriginal and Torres Strait Islanders' engagement with tertiary cancer care services and ultimately contribute to enhanced outcomes [74].

A Qld study found for Aboriginal and Torres Strait Islander people cancer survivors that it is important to establish a strong therapeutic relationship between patients and tertiary and primary health professionals [73]. Discharge summaries or care plans at discharge for survivors and GPs and the provision of access to a range of allied health services can assist survival outcomes. It is also necessary to recognise the diverse range of needs and preferences of cancer survivors.

## Barriers

A number of factors have been identified as preventing early detection of cancer in Aboriginal and Torres Strait Islander people. These factors, which contribute to the delayed diagnosis of cancer, include contextual factors, such as the intergenerational impact of colonisation, racism and socioeconomic deprivation, which have negatively impacted on Aboriginal people's trust of healthcare professionals. Other factors are health service-related, including low accessibility to health services, long waiting periods, inadequate numbers of Aboriginal professionals and high staff turnover; and issues related to patient appraisal of symptoms and decision-making, such as fear of cancer and denial of symptoms have resulted in delays in seeking health care [79].

Distance to primary health care services and poor availability of services in remote areas, including cancer services [102], have been identified as presenting barriers to accessing primary health care services. These barriers are experienced, in particular, by Aboriginal and Torres Strait Islander people [103]. It is generally accepted that inadequate access to primary health care services contributes to the poor health status of Aboriginal and Torres Strait Islander people [91].

The lack of cancer services in regional and remote areas has been noted as contributing to the particularly poor outcomes of patients living in rural areas [102, 104, 105]. The larger numbers of Aboriginal and Torres Strait Islander people living in remote areas relative to

non-Indigenous people means that they are disproportionately disadvantaged. Factors such as the location and accessibility of a health service have been shown to influence the extent to which Aboriginal and Torres Strait Islander people present for diagnosis and continue with treatment [88, 106].

In addition to logistical difficulties, other barriers to the use of cancer health services by Aboriginal and Torres Strait Islander people have been described [107] and include:

- costs associated with consultation fees, medicines, transport and lost wages [103]
- poorer access to community controlled health organisations in metropolitan and regional areas compared to remote areas [103]
- poor collaboration between different parts of the health system [103]
- fear or lack of trust of mainstream health services [20, 21, 108-110]
- cultural misunderstandings, poor communication and experiences of discrimination by mainstream practitioners [20, 21, 108-110]
- fatalistic or differing cultural beliefs about cancer, including feelings of shame [20, 21, 108-110].

## Programs and services

Selected information on some of the key programs and services aimed at preventing, treating and managing cancer are set out below. Initiatives operating at a national level are included, but the information does not cover all programs and services in operation.

### Current national programs

#### Screening programs

Screening programs are important mechanisms in the early detection of cancer as they increase people's awareness of cancer symptoms and encourage them to seek medical attention [19]. Such programs are an important strategy in reducing the incidence and mortality from these cancers as early detection provides an opportunity for treatment which can lead to significantly improved outcomes.

In Australia, there are a number of Government-funded, population based screening activities for the early detection of cancer. These are BreastScreen Australia, the National Bowel Cancer Screening Program (NBCSP) and the National Cervical Screening Program (NSCP). These programs are available free of charge to those who are eligible [111]. Participation in these programs is strongly encouraged for early detection of disease, providing an opportunity for timely intervention to reduce invasive disease and significantly improve outcomes and mortality from these cancers.

Lower participation by Aboriginal and Torres Strait Islander people than non-Indigenous people is reported in all three national population cancer screening programs [26]. The challenges associated with engaging Aboriginal and Torres Strait Islander people in screening programs are complex and lower participation cannot be attributed purely to socio-demographic factors [112]. Multiple barriers to participation exist and include individual knowledge and experiences and limitations in the screening program itself [81, 113, 114]. Another issue is that cancer risk may not be the most salient and immediate concern for vulnerable people who are dealing with other serious health and social issues [115, 116]. In recognition of the particular requirements of Aboriginal and Torres Strait Islander people, informative materials, such as flyers and DVDs, which cater specifically for Aboriginal and Torres Strait Islander consumers have been developed [68].

#### Breast cancer

##### BreastScreen Australia

The national breast screening program, BreastScreen Australia, was established in 1991 as the National Program for the Early Detection of Breast Cancer [117]. The program aims to reduce morbidity and mortality from breast cancer through early detection using screening mammography. The federally-funded screening program provides free two-yearly screening mammograms to women aged 40 and over, and actively invites women aged 50–74 years to have a screening. The mammogram is performed at a screening unit which can be operated through a hospital, health service or a mobile van that travels to rural and remote locations across Australia.

The lower survival for breast cancer among Aboriginal and Torres Strait Islander women noted earlier can be partly explained by lower participation in the BreastScreen Australia early detection program [117, 118]. In 2014-15, participation of Aboriginal and Torres Strait Islander women in the program was 37% compared with 53% for non-Indigenous women. This level of participation for Aboriginal and Torres Strait Islander women has been consistent for a number of years.

## Bowel cancer

### National Bowel Cancer Screening Program (NBCSP)

In 2006, Australia introduced a formal, government-funded, population-based bowel cancer screening program [119]. The NBCSP aims to reduce morbidity and mortality from bowel cancer by screening target population groups for early detection of the disease. Eligible people are sent a faecal occult blood test (FOBT) kit which is used to detect microscopic traces of blood in a person's faeces that may be a sign of bowel cancer. The test requires people to complete a FOBT in their own home and send the sample to a pathology laboratory for analysis. The program is currently being expanded so that by 2020 all Australians aged between 50 and 74 will receive a FOBT kit every two years.

It is estimated that the participation rate for Aboriginal and Torres Strait Islander people aged 50–74 who were invited to participate in 2015–2016 was 20%; this compares with an estimated participation rate for non-Indigenous people of 43% [119].

Suggested reasons for this lower rate of participation of Aboriginal and Torres Strait Islander people in the NBCSP are listed below [60, 115]:

#### Individual

- poor knowledge and awareness of bowel cancer and screening options
- language/literacy barriers
- fatalistic beliefs regarding cancer
- absence of symptoms of cancer
- embarrassment about the sensitive nature of the topic and
- lack of confidence in carrying out the test.

#### Health service

- lack of support from health workers
- lack of health promotion materials in Indigenous languages and
- poor understanding of the cultural needs of Aboriginal and Torres Strait Islander people.

#### Screening program

- recruitment via Medicare
- distribution of screening kits directly to participants via post
- recording of Indigenous status via self-identification at time of screening and
- necessity for participants to have access to privacy and appropriate storage facilities.

The NBCSP relies on self-reporting of Indigenous status on registration forms and so if this information is missing it could affect the accuracy of the participation rate calculated. This could lead to the accuracy of analysis conducted and the conclusions drawn not being fully accurate.

In 2015–2016, Aboriginal and Torres Strait Islander participants in the NBCSP had a higher screening positivity rate than non-Indigenous people (11% compared with 8.2%) [119]. They also had a lower follow up diagnostic assessment rate (53%) than non-Indigenous people (68%). There was a longer median time between positive screen and assessment for Aboriginal and Torres Strait Islander participants (76 days) than for non-Indigenous people (54 days).

## Cervical cancer

### National Cervical Screening Program (NCSP)

The NCSP aims to detect and treat abnormalities in the precancerous stage before they possibly progress to cervical cancer [39]. Cervical screening is not provided by a customised service, but forms part of primary health care. Therefore, women choosing to have a cervical screening test through any health-care provider are considered to be part of the NCSP.

The NCSP previously recommended that all women aged 18 to 69 who have been sexually active, including women who have had the HPV vaccine, have a cervical screening test (the Pap smear test) every two years. Changes to the NCSP took place from December 2017 and all women aged 25 to 75 years are now invited to undertake an HPV (cervical screening) test every 5 years [39]. While the current Pap smear test can detect abnormal cell changes, the new cervical screening test will detect the HPV infection that can cause the abnormal cell changes, prior to the development of cancer. HPV vaccinated women will still require cervical screening as the HPV vaccine does not protect against all types of HPV that cause cervical cancer. A national cancer screening register has been established to support the renewed program.

National participation data for Aboriginal and Torres Strait Islander women in cervical screening is not available as Indigenous status is not included on all pathology forms which provide the information for screening registers [39]. However, progress in this area is being made through the Aboriginal and Torres Strait Islander primary health-care national key performance indicators (nKPIs) data collection which indicates that 28% of regular female Aboriginal and Torres Strait Islander clients had a cervical screening test in the two years as at June 2016; 36% had a cervical screening test in the previous three years; and 44% had a screening test in the previous five years [120].

These findings are confirmed by studies in Qld [121, 122] which suggest that Aboriginal and Torres Strait Islander women are well under-screened and the participation gap between Aboriginal and Torres Strait Islander and non-Indigenous women stands at between 20–30%. This gap, and the resulting failure to detect abnormalities in the precancerous stage, may account for the higher cervical cancer incidence and mortality rates found for Aboriginal and Torres Strait Islander women. Increasing participation in cervical screening to detect precancerous abnormalities leads to the prevention of cancers developing and reducing the incidence of malignant disease [39].

## Increasing participation in screening programs

The need for flexibility in delivery of early detection services has been acknowledged by some services who have designed strategies and initiatives which are culturally sensitive and appropriate to the knowledge, attitudes and beliefs of Aboriginal and Torres Strait Islander people. BreastScreen Australia is noted for being particularly innovative and accommodating. BreastScreen workers liaise closely with Aboriginal Health Workers and Aboriginal and Torres Strait Islander community groups to increase acceptance of screening [117, 123]. In addition, it arranges group bookings for Aboriginal and Torres Strait Islander women who would prefer to attend as a group and some locally based programs allow women to 'drop in' or attend as last minute clients – these have been identified as key facilitators to promoting attendance [81]. Many state and territory BreastScreen programs provide transport to and from screening clinics (particularly for those living in remote regions). This has been frequently shown to be another useful facilitator and operates in many locations [81, 113]. BreastScreen WA's mobile screening service is another effective means of circumventing the logistical obstacles many Aboriginal and Torres Strait Islander women face.

The results of a project in Qld, Closing the Gap in Breast Cancer Screening, confirms that the existing 'one-size-fits-all' model may not necessarily suit Aboriginal and Torres Strait Islander women [117]. This project aimed to address barriers to screening for Aboriginal and Torres Strait Islander women through culturally appropriate messages, art shows and partnerships with local Aboriginal and Torres Strait Islander groups, in order to build trust, educate and support Aboriginal and Torres Strait Islander women to attend BreastScreen Australia. The project reported an increase in Aboriginal and Torres Strait Islander participation from 49% to 56% in 2 years.

There has been criticism of the way in which cancer screening programs developed for the general population work for the Aboriginal and Torres Strait Islander populations. For example, Christou et al noted that there were many barriers to screening uptake as well as follow-up and treatment that arose from both socio-cultural and behavioural barriers affecting the individual as well as structural barriers related to access, economic issues and provider related [115]. In response to such criticism, the Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–2023 aims to develop a more flexible health system to better support Aboriginal people [90]. This demonstrates that the need for adaptability in the delivery of health care is being recognised.

The need for flexibility in the delivery of early detection services to Aboriginal and Torres Strait Islander people is underlined by the introduction of the National Indigenous Bowel Screening Project [124]. This has been initiated with the aim of developing an effective national approach to address bowel cancer awareness and screening for Aboriginal and Torres Strait Islander people [68]. Starting from 2016–2017, three years of funding has been allocated to pilot and evaluate a range of strategies to increase NBCSP participation in up to 50 Aboriginal and Torres Strait Islander primary health care services to determine the most effective model/strategies for potential national implementation. The pilot is underway and with participating sites having screening kits which are offered by health professionals as an alternative to the existing direct mail approach and will assess different levels of implementation training and support for participating services.

## National initiatives to improve cancer care

There are a number of organisations which have initiatives in place aimed at improving cancer care in primary care settings. These offer a range of services including providing information and education to consumers and health professionals and providing practical, emotional and financial support. Most charge no fee for their service and many are staffed by volunteers. Some have initiatives developed specifically for Aboriginal and Torres Strait Islander people.

- Cancer Australia – works to reduce the impact of cancer on Aboriginal and Torres Strait Islander people [125] by:
  - raising awareness of risk factors and promoting awareness and early detection for the community
  - developing evidence-based information and resources for Aboriginal and Torres Strait Islander people affected by cancer, such as *My lung cancer pathway* [126]
  - providing evidence-based cancer information and training resources to Aboriginal and Torres Strait Islander Health Workers
  - increasing understanding of best-practice health care and support, and
  - supporting research.
- Cancer Council Australia and the Cancer Councils in each jurisdiction – among the activities they undertake are:
  - providing cancer research grants
  - providing information on all aspects of cancer
  - running detection and prevention programs to reduce the risk of cancer
  - coordinating cancer support groups, services and programs
  - organising events to raise funds to support cancer control activities
  - providing information and resources for the Aboriginal and Torres Strait Islander community and health workers [59].
- Many Cancer Councils have also increasingly become engaged in issues related to the disparities in cancer outcomes for Aboriginal and Torres Strait Islander people [127, 128].
- Breast Cancer Network – the peak national organisation for those affected by breast cancer supports, informs, represents and connects people affected by breast cancer [129].
- McGrath Foundation – raises money to fund specialist McGrath Breast Care Nurses who manage the care of breast cancer patients throughout the course of their treatment [130].
- Leukaemia Foundation – funds research and provides free services to support people with blood cancer and related blood disorders, and their families [131].
- The National Indigenous Cancer Network – established to improve outcomes for Indigenous people with cancer, including their carers, families and communities. NICaN brings together Indigenous audiences, cancer survivors, service providers, researchers and health professionals, the private sector and government organisations (<http://www.nican.info>).

## Policies and strategies

There are very few national policies and strategies that focus specifically on cancer in the Aboriginal and Torres Strait Islander population. The National Aboriginal and Torres Strait Islander Cancer Framework is therefore significant as the first national approach to addressing the gap in cancer outcomes that currently exists between Aboriginal and Torres Strait Islander people and the non-Indigenous population [132]. However, over the past 30 years, there have been a number of relevant strategies and frameworks developed addressing cancer in the general population, and broader aspects of Aboriginal and Torres Strait Islander health. A selection of national policy developments relevant to addressing cancer among Aboriginal and Torres Strait Islander people are described briefly below.

### Selected national policy developments relevant to addressing cancer among Aboriginal and Torres Strait Islander people

2018	Lung Cancer Framework: Principles for Best Practice Lung Cancer Care in Australia is released
2016	National Framework for Gynaecological Cancer Control is released
2015	First National Aboriginal and Torres Strait Islander Cancer Framework is released
2015	Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan is released
2014	Second Cancer Australia Strategic Plan 2014–2019 is published
2013	First National Aboriginal and Torres Strait Islander Health Plan 2013–2023 is published
2011	First Cancer Australia Strategic Plan 2011–2014 is published
2008	National Cancer Data Strategy for Australia is released
2003	Report Optimising Cancer Care in Australia is published
1998	First National health priority areas cancer control report is published
1996	Cancer becomes one of four National health priority areas (NHPA)
1988	Health for all Australians report is released
1987	First National Cancer Prevention Policy for Australia is published

It was not until the late 1980s that national cancer control strategies and policies began to be developed [133]. In 1987, the first National Cancer Prevention Policy for Australia, was published by the Australian Cancer Society (ACS) (now the Cancer Council Australia) based on a series of expert workshops [134]. It outlined what prevention activities were currently being undertaken, what should be undertaken and suggested a number of goals, targets and strategies in the areas of cancer prevention and early detection and screening. This policy has been updated many times over the years [133] and is still in publication as the *National cancer control policy* [135].

The following year, in 1988, the *Health for all Australians* report, commissioned by the Australian Health Ministers' Advisory Council (AHMAC), recognised that cancers could be influenced by primary or secondary prevention strategies [136]. The report recommended nine goals and 15 targets related to cancers, based on those put forward by the National Cancer Prevention Policy for Australia. Cancer prevention and strategies relating to breast, cervical and skin cancer and tobacco smoking were recommended as initial priorities under the National Program for Better Health. These were then endorsed at the Australian Health Ministers Conference and funding was provided.

In 1996, cancer control was identified as one of four National health priority areas (NHPA). This led, the following year, to the publication of the *First report on national health priority areas 1996*, which outlined 26 indicators spanning the continuum of cancer care, and included outcome indicators, indicators relating to patient satisfaction and the creation of hospital based cancer registries [137].

In 1998, the first NHPA cancer control report was produced [138]. It identified a number of opportunities for improvements in cancer control, including within 'special populations such as Indigenous people' [138].

In 2003, the report *Optimising cancer care in Australia* was jointly developed by The Cancer Council Australia, the Clinical Oncological Society of Australia (COSA) and the National Cancer Control Initiative (NCCI), with strong consumer input [139]. This report made 12 key recommendations, including that the needs of Aboriginal and Torres Strait Islander people be the focus of efforts to bridge gaps in access to and utilisation of culturally sensitive cancer services.

In 2008, the National Cancer Data Strategy for Australia aimed to provide direction for collaborative efforts to increase data availability, consistency and quality [140]. It reported that although Indigenous status is recorded by cancer registries, data quality is poor, and recommended that the quality of Indigenous markers in hospital and death statistics collections needs to improve if cancer registries are to have better data.

In 2011, Cancer Australia published the first Cancer Australia strategic plan 2011–2014, which aimed to identify future trends in national cancer control and to outline strategies for the organisation to improve outcomes for all Australians diagnosed with cancer [141]. It was followed in 2014, by the Cancer Australia strategic plan 2014–2019, which had an increased focus on improving quality of cancer care and outcomes for Aboriginal and Torres Strait Islander people [142].

In 2013, the National Aboriginal and Torres Strait Islander Health Plan 2013–2023 (the *Health plan*) was developed to provide a long-term, evidence-based policy framework approach to closing the gap in disadvantage experienced by Aboriginal and Torres Strait Islander people [143]. The *Health plan* emphasises the importance of culture in the health of Aboriginal and Torres Strait Islander people and the rights



of individuals to a safe, healthy and empowered life. Its vision is for the Australian health system to be free of racism and inequity and all Aboriginal and Torres Strait Islander people to have access to health services that are effective, high quality, appropriate and affordable. This led to the publication of the Implementation plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–2023 in 2015 [90], which outlines the strategies, actions and deliverables required for the Australian Government and other key stakeholders to implement the *Health plan*.

The first National Aboriginal and Torres Strait Islander Cancer Framework (the *Framework*) was released in 2015, to address disparities and improve cancer outcomes for Aboriginal and Torres Strait Islander people [56]. It provides strategic direction by setting out seven priority areas for action and suggests enablers that may help in planning or reviewing strategies to address each of the priority areas. The *Framework* aims to improve cancer outcomes for Aboriginal and Torres Strait Islander people by ensuring timely access to good quality and appropriate cancer related services across the cancer continuum.

In 2016, Cancer Australia released the National Framework for Gynaecological Cancer Control to guide future directions in national gynaecological cancer control to improve outcomes for women affected, as well as their families and carers [144]. It aims to ensure the provision of best practice and culturally appropriate care to women across Australia by offering strategies across six priority areas, of which one pertains specifically to improving outcomes for Aboriginal and Torres Strait Islander women.

In 2018, Cancer Australia released the Lung Cancer Framework: Principles for Best Practice Lung Cancer Care in Australia [145]. It aims to improve the outcomes and experiences of people affected by lung cancer by supporting the uptake of five principles: patient-centred care; multidisciplinary care; timely access to evidence-based care; coordination, communication and continuity of care and data-driven improvements.

## Future directions

The National Aboriginal and Torres Strait Islander Cancer Framework (the *Framework*) provides guidance for individuals, communities, organisations and governments [56]. The *Framework* was developed in partnership with Menzies School of Health Research, and was informed by a systematic review of the evidence and extensive national consultations. The parties involved in these consultations included Aboriginal and Torres Strait Islander people affected by cancer, health professionals working with Aboriginal and Torres Strait Islander people and experts in Indigenous cancer control. The *Framework* outlined seven evidence-based priority areas for action as follows:

- improving knowledge and attitudes about cancer
- focusing prevention activities
- increasing participation in screening and immunisation
- ensuring early diagnosis
- delivering optimal and culturally appropriate treatment and care
- involving, informing and supporting families and carers
- strengthening the capacity of cancer-related services to meet the needs of Aboriginal and Torres Strait Islander people.

Each of these priorities was accompanied by a number of enablers to assist in planning or reviewing strategies to address that priority. The enablers provide flexible approaches to meeting the priorities that allow for local context and needs.

The development of the *Framework* has been responsible for gathering national support and agreement on the priorities and for creating a high level of expectation around the ability to address the growing cancer disparity [146]. Cancer Australia has since commenced a number of projects and initiatives that focus on one or more of the priorities identified by the *Framework*. One project aims to identify critical success factors and effective approaches to increasing mammographic screening participation for Aboriginal and Torres Strait Islander women [147]. A leadership group on Aboriginal and Torres Strait Islander cancer control tasked with driving a shared agenda to improve cancer outcomes has also been established [148]. In addition, the development of a monitoring and reporting plan for the *Framework* is underway.

Quality data are critical to understanding the variations in cancer care and outcomes of Aboriginal and Torres Strait Islander people, and to inform policy, service provision and clinical practice initiatives to improve those outcomes. However, it has been repeatedly reported in the literature and by the *Framework*, that current data are inadequate or incomplete, and there is a significant need for improved local, jurisdictional and national data on Aboriginal and Torres Strait Islander people with cancer [56, 149-151]. In particular, the need for primary

healthcare services to address the under identification of Aboriginal and Torres Strait Islander status in data registries. A project currently underway in SA, which is likely to have relevance to other regions, aims to develop an integrated comprehensive, cancer monitoring and surveillance system for Aboriginal people, while also incorporating their experiences with cancer services [149].

Both the *Framework* and the literature have identified a need for a more supportive and culturally appropriate approach across the cancer care continuum for Aboriginal and Torres Strait Islander people [56, 77, 151, 152]. The Wellbeing Framework for Aboriginal and Torres Strait Islander Peoples Living with Chronic Disease, (*Wellbeing framework*), aims to assist healthcare services to improve the quality of life and quality of care, as well as health outcomes, for Aboriginal and Torres Strait Islander people living with chronic disease [153]. This addresses the identified need for more supportive and culturally appropriate care as it attempts to incorporate the social, emotional, cultural and spiritual aspects of health and wellbeing, as well as the physical aspects.

The *Wellbeing framework* is underpinned by two core values, which are considered fundamental to the care of Aboriginal and Torres Strait Islander people [153, 154]. These core values highlight that wellbeing is supported by:

- upholding people's identities in connection to culture, spirituality, families, communities and country and
- having culturally safe primary healthcare services in place.

The *Wellbeing framework* consists of four essential elements for supporting the wellbeing of Aboriginal and Torres Strait Islander people living with chronic disease [153, 154]. These show the importance of having:

- locally defined, culturally safe primary health care services
- appropriately skilled and culturally competent health care teams
- holistic care throughout the lifespan
- best practice care that addresses the particular needs of a community.

The *Wellbeing framework* suggests a number of practical and measurable applications for applying or achieving the underlying principles of each element. It has the capacity to be adapted by primary healthcare services, in consultation with the communities they serve, to more effectively meet the chronic and cancer care needs of their communities [153, 154].

The Leadership Group on Aboriginal and Torres Strait Islander Cancer Control was established in 2016-17 to:

- provide strategic advice and specialist expertise in Indigenous cancer control
- encourage cross-sector collaboration in addressing the priorities in the National Aboriginal and Torres Strait Islander Cancer Framework
- share knowledge across the sector to leverage opportunities.

## Concluding comments

Despite considerable improvements in cancer detection and treatment over recent decades, Aboriginal and Torres Strait Islander people diagnosed with cancer generally experience poorer outcomes than non-Indigenous people for an equivalent stage of disease [27, 97]. This is highlighted by statistics which showed that, despite lower rates of prevalence and hospitalisation for all cancers combined for Aboriginal and Torres Strait Islander people compared with non-Indigenous people, between 1998 and 2015, the age-standardised mortality rate ranged from 195 to 246 per 100,000 while the rate for non-Indigenous people decreased from 194 to 164 per 100,000 [2].

Furthermore for 2007–2014, while 65% of non-Indigenous people had a chance of surviving five years after receiving a cancer diagnosis, only 50% of Aboriginal and Torres Strait Islander people did [2].

The disparities are particularly pronounced for some specific cancers – for lung cancer the age-standardised incidence rate for Aboriginal and Torres Strait Islander people was twice that for non-Indigenous people, while for cervical cancer the rate was 2.5 times the rate for non-Indigenous people for 2009–2013 [2].

The factors contributing to these poorer outcomes among Aboriginal and Torres Strait Islander people are complex. They reflect a broad range of historical, social and cultural determinants and the contribution of lifestyle and other health risk factors [6], combined with lower participation in screening programs, later diagnosis, lower uptake and completion of cancer treatment, and the presence of other chronic diseases [27, 98, 155]. Addressing the various factors that contribute to the development of cancer among Aboriginal and Torres Strait

Islander people is important, but improvements in some of these areas, particularly in reducing lifestyle and behavioural risk factors, are likely to take some time to be reflected in better outcomes.

Current deficiencies in the prevention and management of cancer suggest there is considerable scope for better services that should lead to improvements in the short to medium term. Effective cancer prevention and management programs that are tailored to community needs and are culturally appropriate are vital for the current and future health of Aboriginal and Torres Strait Islander people [56, 57]. Providing effective cancer prevention and management also requires improved access to both high quality primary health care services and tertiary specialist services. Effective and innovative programs for the prevention and management of cancer among Aboriginal and Torres Strait Islander people do exist on an individual basis and, in some cases, the efforts made to engage Aboriginal and Torres Strait Islander people in screening programs, in particular, are impressive. However, a more coordinated, cohesive national approach is also required.

Reducing the impact of cancer among Aboriginal and Torres Strait Islander people is a crucial aspect in 'closing the gap' in health outcomes. *The National Aboriginal and Torres Strait Islander cancer framework* [56] may be an important first step in addressing the current disparity in cancer outcomes and raises the probability of real progress being made. Cancer Australia has recently released the *Optimal care pathway for Aboriginal and Torres Strait Islander people* which recommends new approaches to cancer care and with the aim of reducing disparities and improving outcomes and experiences for Aboriginal and Torres Strait Islander people with cancer [156]. As encouraging as these developments are, substantial improvements will also depend upon the effective implementation of comprehensive strategies and policies that address the complexity of the factors underlying the disadvantages experienced by Aboriginal and Torres Strait Islander people. Action beyond the health service sector that addresses the broader historical, social and cultural determinants of health are also required if real progress is to be made [6].

## Abbreviations

**AATSIHS** – Aboriginal and Torres Strait Islander Health Survey

**AIHW** – Australian Institute of Health and Welfare

**BEACH** – Bettering the Evaluation and Care of Health

**DALY** – disability-adjusted life years

**DNA** – Deoxyribonucleic acid

**GP** – General practitioner

**NHPA** – National health priority areas

**HPV** – Human Papilloma Virus

**NICAN** – National Indigenous Cancer Network

**NBCSP** – National Bowel Cancer Screening Program

**NSCP** – National Cervical Screening Program

**RR** – Rate ratio

**YLD** – years lived with a disability

**YLL** – years of life lost

### States and Territories

**ACT** – Australian Capital Territory

**nKPI** – National key performance Indicator

**NSW** – New South Wales

**NT** – Northern Territory

**Qld** – Queensland

**SA** – South Australia

**Tas** – Tasmania

**Vic** – Victoria

**WA** – Western Australia

## Appendix 1: Data sources and limitations

The statistical information provided in this review draws on data from a number of sources. The various limitations associated with the data are discussed briefly below:

### Incidence

Data on incidence of cancer among Aboriginal and Torres Strait Islander people is typically only available for NSW, Vic, Qld, WA and the NT, as these jurisdictions have sufficient levels of identification and sufficient incidence of cancer to support analysis [2]. Due to the incomplete identification of Aboriginal and Torres Strait Islander status, the incidence figures may underestimate the true difference between Aboriginal and Torres Strait Islander and non-Indigenous rates.

### Prevalence

Data on prevalence of cancer among Aboriginal and Torres Strait Islander people is typically only available for NSW, Vic, Qld, WA and the NT, as these jurisdictions have sufficient levels of identification and sufficient prevalence of cancer to support analysis [2]. Age-standardised prevalence figures by age and gender for Aboriginal and Torres Strait Islander people are available to the end of 2013. Due to the incomplete identification of Aboriginal and Torres Strait Islander status, the prevalence figures may underestimate the true difference between Aboriginal and Torres Strait Islander and non-Indigenous rates.

### Health service utilisation

Hospitalisation figures can provide information about the impact of chronic diseases (such as cancer) on a population, but should be interpreted with caution. Hospitalisation figures are for 'separations', and as there can be multiple separations for the same individual, hospital records do not necessarily reflect the prevalence of a disease in the population [46]. Due to the incomplete identification of Aboriginal and Torres Strait Islander status, the hospitalisation figures may underestimate the true difference between Aboriginal and Torres Strait Islander and non-Indigenous rates.

The overall quality of data provided for Indigenous status varies between states and territories. For analysis and reporting purposes, Indigenous identification in hospital statistics has been considered adequate in all jurisdictions since 2013–14 [46]. Prior to this, Indigenous identification in hospital statistics was considered adequate for NSW, Vic, Qld, WA, SA and public hospitals in the NT.

### Mortality

Death data for Aboriginal and Torres Strait Islander people are typically only available for NSW, Qld, WA, SA and the NT, as these jurisdictions have sufficient levels of identification and sufficient numbers of deaths to support analysis [2]. Due to the incomplete identification of Aboriginal and Torres Strait Islander status, the mortality figures may underestimate the true difference between Aboriginal and Torres Strait Islander and non-Indigenous rates.

### Burden of disease

As noted above, the quality of Indigenous status in cancer incidence, prevalence and mortality data varies by jurisdiction and year of collection and may impact upon the fatal and non-fatal burden estimates for cancer.

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