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Summary of cancer among Aboriginal and Torres Strait Islander people

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Summary of cancer among Aboriginal and Torres Strait Islander people



Australian Indigenous HealthInfoNet

The Australian Indigenous HealthInfoNet's mission is to contribute to improvements in Aboriginal and Torres Strait Islander health by making relevant, high quality knowledge and information easily accessible to policy makers, health service providers, program managers, clinicians and other health professionals (including Aboriginal and Torres Strait Islander health workers) and researchers. The HealthInfoNet also provides easy-to-read and summarised material for students and the general community.

The HealthInfoNet achieves its mission by undertaking research into various aspects of Aboriginal and Torres Strait Islander health and disseminating the results (and other relevant knowledge and information) mainly via its website (healthinonet.ecu.edu.au). The research involves analysis and synthesis of data and other information obtained from academic, professional, government and other sources. The HealthInfoNet's work in knowledge exchange aims to facilitate the transfer of pure and applied research into policy and practice to address the needs of a wide range of users.

Recognition statement

The Australian Indigenous HealthInfoNet recognises and acknowledges the sovereignty of Aboriginal and Torres Strait Islander people as the original custodians of the country. Aboriginal and Torres Strait cultures are persistent and enduring, continuing unbroken from the past to the present, characterised by resilience and a strong sense of purpose and identity despite the undeniably negative impacts of colonisation and dispossession. Aboriginal and Torres Strait Islander people throughout the country represent a diverse range of people, communities and groups each with unique identity, cultural practices and spiritualities. We recognise that the current health status of Aboriginal and Torres Strait Islander people has been significantly impacted by past and present practices and policies.

We acknowledge and pay our deepest respects to Elders past and present throughout the country. In particular, we pay our respects to the Whadjuk Nyoongar peoples of Western Australia on whose country our offices are located.

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Further information

This Summary is based on the publication: Haigh M, Burns J, Potter C, Elwell M, Hollows M, Mundy J, Taylor E, Thompson S. (2018) Review of cancer among Aboriginal and Torres Strait Islander people. *Australian Indigenous HealthBulletin* 18(3).

The summary, cancer reviews and more information about cancer among Aboriginal and Torres Strait Islander people can be viewed at: <https://healthinonet.ecu.edu.au/learn/health-topics/cancer>.

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Featured artwork:
Karnta by Corinne Nampijinpa Ryan

Why do a Summary?

This plain language and visual summary provides key information about cancer among Aboriginal and Torres Strait Islander people in Australia in a style that is easy to engage with and does not require our readers to have an academic or medical background. The summary provides information on the extent of cancer among Aboriginal and Torres Strait Islander people, the risk factors that contribute to cancer and strategies in place to reduce its impact on individuals and communities.

This summary draws mostly on journal publications, government reports, national data collections and national surveys accessed through the HealthInfoNet's Bibliography. Please note that statistics presented do not always include all states and territories, see sources for details.

When referring to Australia's Indigenous people, the HealthInfoNet prefers to use the terms Aboriginal, Torres Strait Islander, or Aboriginal and Torres Strait Islander. Although, if we are quoting from a source that uses the word 'Indigenous' we will use that term. If you have any concerns you are advised to contact the HealthInfoNet for further information.

Introduction

Cancer is a major cause of sickness in Australia and has a large effect on families and communities [1]. Cancer is the term used for a number of diseases that cause damage to healthy body cells causing them to grow abnormally and spread to other areas [2].

Cancer can start almost anywhere in the body [2] and there are more than 200 types of cancer [3]. The type of cancer usually relates to the body part affected (for example, lung cancer affects the lungs). This is known as the primary site. When cancer cells travel and spread to other parts of the body the process is known as 'metastasis' [4].

Aboriginal and Torres Strait Islander people are particularly at risk for some types of cancer [5]. Some reasons for this include:

- high rates of smoking
- low participation in cancer screening services
- high rates of being overweight or obese.

Historical, social and cultural context

The risk of developing cancer is influenced not only by a person's age, family history and behaviour [6], but also by factors relating to their past, their social and financial situation, their cultural background and where they come from and where they live [7].

Aboriginal and Torres Strait Islander people have lived on their traditional lands across Australia, including the islands of the Torres Strait, for many thousands of years [8]. Before colonisation, Aboriginal and Torres Strait Islander people lived in family and community groups and moved across the land as the seasons changed. Colonisation of Australia occurred around 1788 and led to many changes in the way Aboriginal and Torres Strait Islander people lived. These changes had a significant impact on health and wellbeing [8, 9]. The health of Aboriginal and Torres Strait Islander individuals also includes the social, emotional and cultural well-being of their community and the ability to reach their potential to contribute to the community [10]. It is a whole-of-life view (life-death-life).

In some cases, the negative beliefs about cancer that some Aboriginal and Torres Strait Islander people have traditionally held, impact their willingness to participate in screening programs and to make decisions around cancer treatment. Feelings of 'shame' around cancer and a lack of trust in health services have been common [5]. Some beliefs around cancer are that it could be punishment for past wrongdoing [11], the fault of 'white man' because it wasn't seen as a problem before colonisation [12] or that it can be caught from others [11, 12].

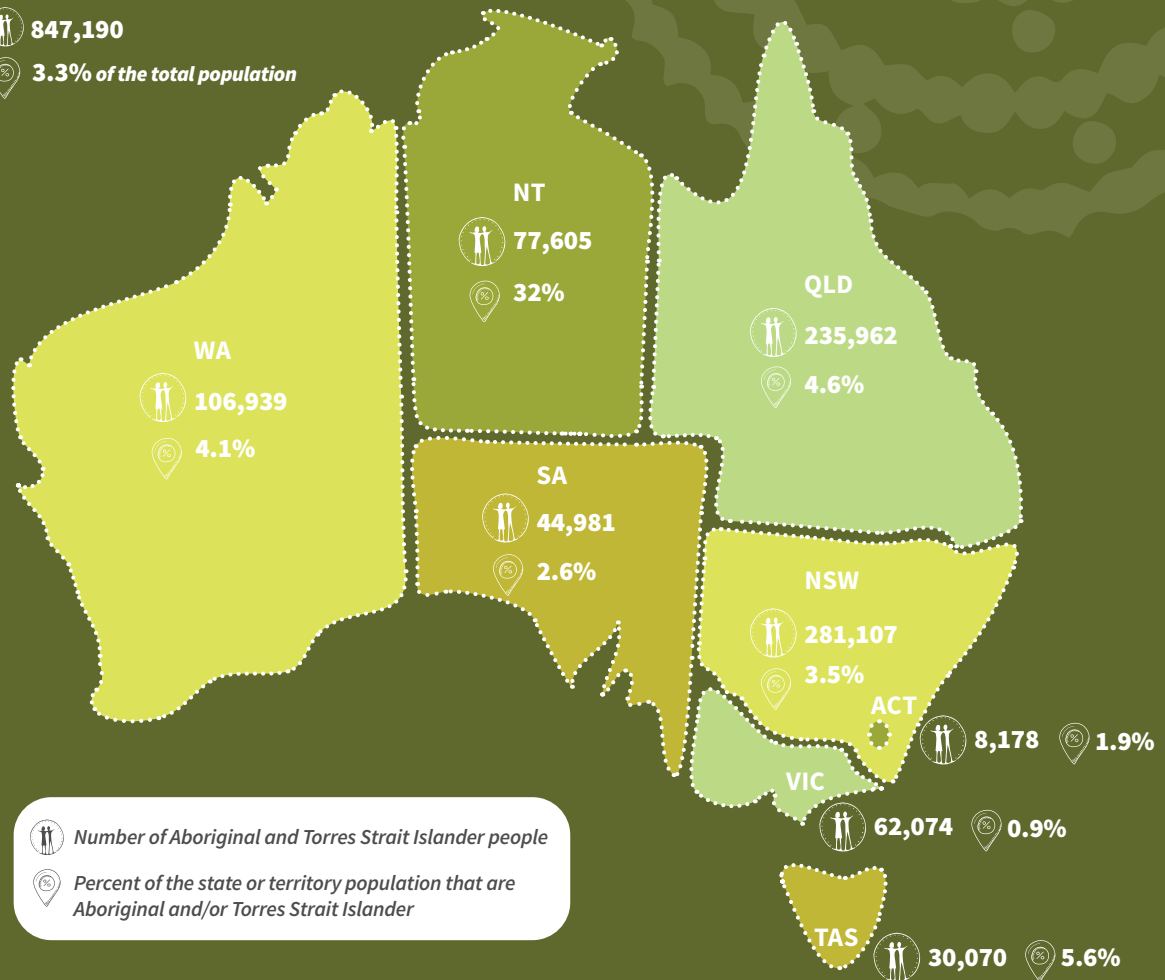


One area of positive change is Aboriginal and Torres Strait Islander self-governance. There has also been an increase in the number of Aboriginal and Torres Strait Islander people in all levels of government [13] and the health workforce. This has led to a shift towards better ways of talking and thinking about Aboriginal and Torres Strait Islander health and wellness, and away from focusing on a 'deficit' approach, particularly in comparisons with non-Indigenous Australians [14].

Aboriginal and Torres Strait Islander people living in Australia, 2019

 847,190

 3.3% of the total population



 Number of Aboriginal and Torres Strait Islander people

 Percent of the state or territory population that are Aboriginal and/or Torres Strait Islander

AIHW, 2019 [15]

Demographic factors

In 2019, the population estimate for Aboriginal and Torres Strait Islander people living in Australia was 847,190 people, comprising 3.3% of the total Australian population [15]. The majority of Aboriginal and Torres Strait Islander people lived in New South Wales (NSW) and Queensland (Qld). While less in numbers, the proportion of Aboriginal and Torres Strait Islander people was highest (32%) in the Northern Territory (NT).

It was estimated that in 2016, more than 60% of Aboriginal and Torres Strait Islander people lived outside of the major cities, with approximately 19% living in remote and very remote areas (Derived from [15]).

The Aboriginal and Torres Strait Islander population has a larger proportion of young people and a smaller proportion of older people [15].

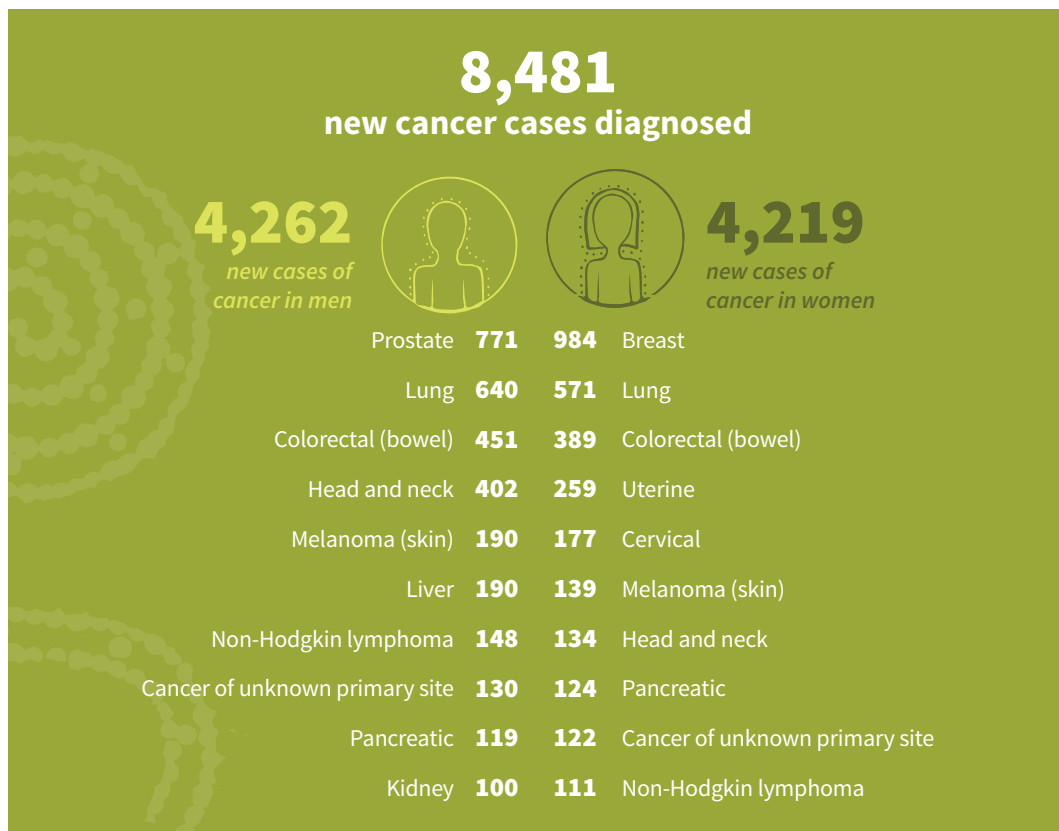
Extent of cancer among Aboriginal and Torres Strait Islander people

This summary is based on national surveys and data that use various ways to measure the extent of cancer. Some of the terms used to talk about these measurements include:

- **incidence** is the number of new cases of cancer in a time period, the **incidence rate** is the number divided by the population of interest
- **prevalence** is the proportion of people living with cancer in a given time period
- **age-standardised rates** allow comparisons between populations that have different age profiles. They are used when comparing Aboriginal and Torres Strait Islander people and non-Indigenous people because as noted above there are more younger people and fewer older Aboriginal and Torres Strait Islander people compared to non-Indigenous people
- **survival** is the likelihood of a person being alive for a given period of time after being diagnosed with cancer.

Combined cancers

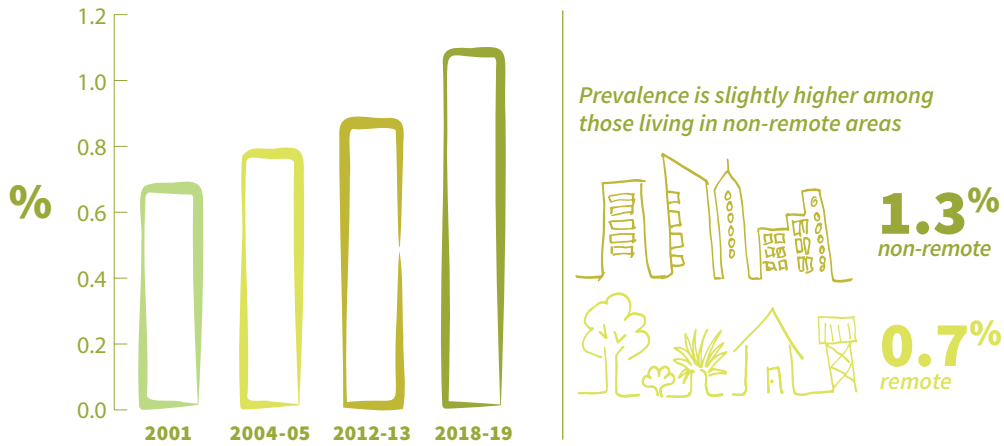
Top ten leading cancers in men and women, 2010-2014



AIHW, 2019 [16]

In 2013, it was estimated that 3,626 Aboriginal and Torres Strait Islander people had been living with cancer in the previous five years [4]. 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). However, in recent surveys it was found that the prevalence has been steadily increasing.

Prevalence of cancer among Aboriginal and Torres Strait Islander people



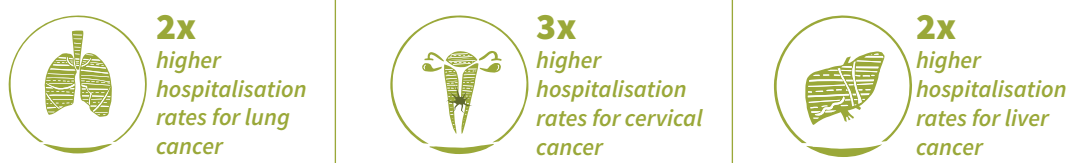
National Aboriginal and Torres Strait Islander Health Survey, 2018-19 [17]

Hospital admissions

In 2017–18, there were 8,447 hospital admissions for cancer among for Aboriginal and Torres Strait Islander people in Australia [18]. This accounts for 3% of all Aboriginal and Torres Strait Islander hospitalisations.

Overall, Aboriginal and Torres Strait Islander people are less likely to be hospitalised for cancer than non-Indigenous people [18]. However, for Aboriginal and Torres Strait Islander people, their average length of stay in hospital has been found to be longer compared with non-Indigenous people [19]. This may be partly explained by difficulties they experience in accessing appropriate health services and issues related to the need for travel to access treatment.

For some specific cancers, the rates of hospitalisation among Aboriginal and Torres Strait Islander people are higher than for non-Indigenous people. In 2014-15, hospitalisation rates were higher for lung and cervical cancers for Aboriginal and Torres Strait Islander people than for non-Indigenous people [20]. Hospitalisation rates were also notably higher for liver cancer for the period 2006-07 to 2010-11 [19].



Cancer survival

Some information is available on survival from cancer among Aboriginal and Torres Strait Islander people [4]. The survival rate for the main cancer types decreases with age.

Likelihood of surviving at least 5 years after diagnosis 2007-2014 [4]



50%
Aboriginal and Torres
Strait Islanders



65%
Non-Indigenous

AIHW, 2018 [4]

Survival rates in 2010-14 for Aboriginal and Torres Strait Islander people were highest for breast cancer in women (77%) and for prostate cancer in men (75%) [16]. Lung cancer had the lowest survival rate for both men and women (10%).

Cancer deaths

Death due to cancer is more common for Aboriginal and Torres Strait Islander people than for non-Indigenous people [4]. In 2012-2016, cancer was responsible for the deaths of 2,917 Aboriginal and Torres Strait Islander people, an average of 583 deaths per year [16].

In 2018, cancers of the lung, trachea (windpipe) and bronchus (major air passages to the lungs) were the fourth leading cause of death for Aboriginal and Torres Strait Islander people [21]. Other types of cancer that are listed in the top 20 leading causes of death for Aboriginal and Torres Strait Islander people in 2018 included; bowel cancer; liver cancer, pancreatic cancer, breast cancer and blood cancers.



Lung cancer is 4th leading cause of ALL DEATHS for Aboriginal and Torres Strait Islander people

2,917 Cancer deaths from 2012-2016,
an average of 583 per year.

AIHW, 2019 [16]

Most common cancers

Lung cancer

From 2010-2014, lung cancer was the most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people with an average of 242 new cases per year, with rates slightly higher for males than females [16]. The incidence of lung cancer increases with age, with the highest rate being for the 65 years and over age group [4].



128
new cases of lung
cancer in men



114
new cases of lung
cancer in women

Lung cancer had the lowest rate of survival in the period of 2010-2014, at less than 10% [16]. From 2011-2015, the rate of deaths due to lung cancer was 1.8 times higher for Aboriginal and Torres Strait Islander people than for non-Indigenous people [4].

Breast cancer



77%
*average five-year
survival rate*

From 2010-2014, breast cancer was the second most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people [16]. An average of 197 Aboriginal and Torres Strait Islander women are diagnosed with breast cancer each year. The five-year survival rate for Aboriginal and Torres

Strait Islander women with breast cancer was 77%. In 2018, there were 40 deaths due to breast cancer among Aboriginal and Torres Strait Islander women, and the rate of deaths was 1.2 times higher than for non-Indigenous people [21]. Poorer outcomes for Aboriginal and Torres Strait Islander people suggest that breast cancers are diagnosed at a later stage when treatment is less effective [19, 22].

Bowel cancer



55%
*average five-year
survival rate*

From 2010-2014, bowel cancer was the third most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people with an average of 168 cases per year [16]. On average Aboriginal and Torres Strait Islander people have a 55% chance on average of surviving five years after a bowel cancer

diagnosis. In 2012-2016, bowel cancer was the second most common cancer causing death among Aboriginal and Torres Strait Islander people. However, reluctance to seek medical advice and medical care for symptoms and late stage diagnosis among Aboriginal and Torres Strait Islander people may mean that incidence and death rates for bowel cancer may be underestimated [22-26].

Prostate cancer



More than 150
*diagnoses of prostate
cancer each year*

From 2010-2014, prostate cancer was the fourth most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people [16]. An average of 154 Aboriginal and Torres Strait Islander men are diagnosed with prostate cancer each year. From 2010-2014, the five year survival rate for

prostate cancer among Aboriginal and Torres Strait Islander men was 75%. There were 81 deaths due to prostate cancer from 2012-2016.

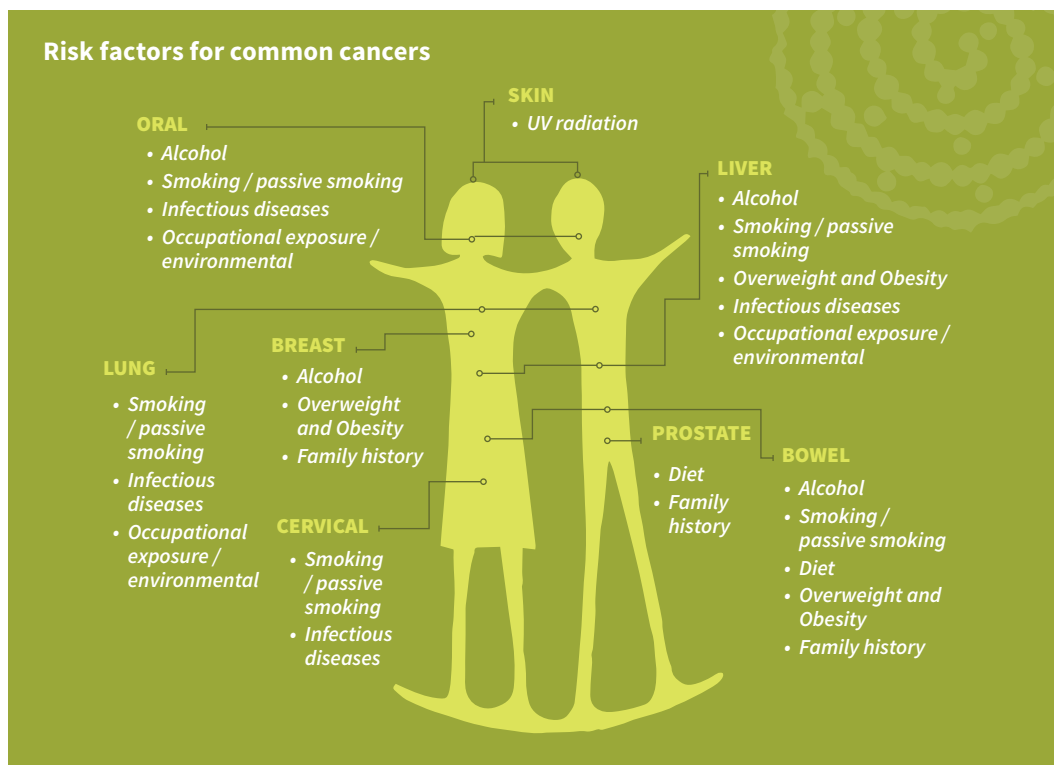
Cervical cancer



3.5x
*higher death rate
than for non-
Indigenous women*

From 2010-2014, an average of 35 Aboriginal and Torres Strait Islander women were diagnosed with cervical cancer each year [16]. Aboriginal and Torres Strait Islander women were 2.5 times more likely to develop cervical cancer than non-Indigenous women [27]. From 2010-2014, the five year survival

rate for cervical cancer was 54% [16]. The rate of deaths due to cervical cancer from 2013-2017 was 3.5 times higher for Aboriginal and Torres Strait Islander women than for non-Indigenous women [27]. Late stage diagnosis and lack of availability of treatment, especially for women in remote areas, are likely reasons for higher cervical cancer incidence and death rates among Aboriginal and Torres Strait Islander women [28].



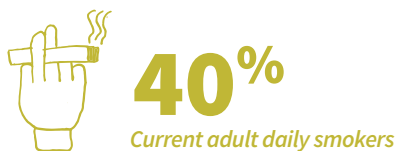
AIHW, 2013 [19]; Moon, et al., 2017 [35]; The Kirby Institute, 2018 [38]; Castle, et al., 2016 [6]

Risk factors that contribute to cancer

Many cancer risk factors are more common in Aboriginal and Torres Strait Islander people than other Australians, these include: smoking and exposure to passive smoke; and being overweight or obese [8]. These risk factors can be modified by changes to behaviour and lifestyle, such as quitting smoking, maintaining a healthy diet, and increasing levels of physical activity. Other risk factors include alcohol consumption, infectious diseases, environmental factors and radiation [6]. However, some people with one or more risk factors may never develop cancer, and other people with none of these risks factors can still develop cancer [29].

Smoking and passive smoking

Tobacco smoking is the greatest risk factor for cancer, and smoking-related cancers generally have a much poorer outlook. Cancers caused by smoking include: lung, oesophagus, larynx, mouth, throat, kidney, bladder, liver, pancreas, cervix and stomach [30]. Rates of tobacco smoking are high among Aboriginal and Torres Strait Islander people.



2018-19 National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) [17]

Passive smoking means breathing in other people's tobacco smoke and this is also a risk factor for cancer.



2014-15 National Aboriginal and Torres Strait Islander Social Survey [31]

Government and community-based interventions like the Tackling Indigenous Smoking program [32] have been running across Australia for a number of years. The good news is that over the past 15 years the number of Aboriginal and Torres Strait Islander adults living in urban areas who smoke has been decreasing [17]. However, among those living in remote areas the number of daily smokers has increased. It is important to continue to reduce the number of young people taking up smoking and to support quit programs.



Number of adult daily smokers in non-remote areas has decreased



Number of adult daily smokers in remote areas has increased

NATSIHS, 2018-19

Alcohol consumption



Some cancers related to alcohol consumption have higher rates for Aboriginal and Torres Strait Islander people. While overall, Aboriginal and Torres Strait Islander people are less likely to consume alcohol than non-Indigenous people, some of those who do, drink at levels considered harmful to health [33, 34]. Binge drinking and regular heavy alcohol consumption are risks for breast, bowel, liver and oral cancers [35]. The 2018-19 NATSIHS reported that among Aboriginal and Torres Strait Islander adults who consumed alcohol, 20% drank at levels exceeding the 2009 guidelines for lifetime health risk [17]. Together, smoking and drinking alcohol at high levels, can multiply a person's chances of developing alcohol-related cancers.

Nutrition, obesity and physical activity



Poor nutrition, being overweight or obese and not doing much exercise are serious risk factors for cancer. The risk for some cancers (bowel, lung, oesophagus, oral cavity, pharynx, stomach and larynx [30]) increases with weight gain, being overweight or obese, regardless of physical activity levels.

Like a lot of Australians, Aboriginal and Torres Strait Islander adults often don't eat the recommended amount of fruit and vegetables [17], and many eat too much junk food [36]. In remote communities with only limited fresh supplies, the diet of Aboriginal and Torres Strait Islander people is generally very low in fruit and vegetable content, high in energy and sugars, and moderately high in fats [37]. The 2018-19 NATSIHS reported that less than half (39%) of Aboriginal and Torres Strait Islander people were eating enough fruit each day, and only 4.1% were eating enough vegetables [17]. The survey also reported that 74% of the Aboriginal and Torres Strait Islander adult population was overweight or obese, and 88% were not getting enough physical activity. All forms of physical activity protect against some cancers, as well as against weight gain.

Infectious diseases



Chronic infectious diseases can cause changes in our body's cells and immune system which can sometimes lead to cancer. A major risk factor for liver cancer is chronic infection with hepatitis B virus (HBV) or with hepatitis C virus (HCV). Both infections have higher rates in the Aboriginal and Torres Strait Islander population than the non-indigenous population [38]. Immunisation for hepatitis B and improved treatments for hepatitis C aim to reduce these risks.

The Human Papilloma Virus (HPV) is a common sexually transmitted infection (STI) and some types of HPV can cause cervical cancer [28]. National HPV vaccination and cervical screening programs are likely to reduce rates of cervical cancer over time. However, reports show that Aboriginal and Torres Strait Islander women are under-screened and there is insufficient information about their HPV vaccinations [27, 38].

Prevention and management

For the effective prevention and treatment of cancer, it is important that health promotion and education approaches recognise the significance and influence of local cultures and focus on capacity building, community empowerment and local ownership.

Some recommendations to reduce rates of cancer and improve cancer outcomes for Aboriginal and Torres Strait Islander people include:

- culturally appropriate early detection programs
- locally supported and targeted intensive lifestyle programs that support individuals to make healthy lifestyle choices and changes
- assessing the support needs of individual patients diagnosed with cancer and linking them with support groups
- developing strong links between Aboriginal and Torres Strait Islander communities, primary health care providers and mainstream cancer care services.

Promoting healthy lifestyles

Healthy lifestyle programs that address smoking, physical activity and nutrition among Aboriginal and Torres Strait Islander people can have positive health effects [7, 39].



Regional Tackling Smoking Healthy Lifestyle Teams

The Tackling Indigenous Smoking (TIS) program is part of the Australian Government's Indigenous Australians' Health Programme. Regional teams were established in communities across the country to:

- raise awareness of the link between tobacco smoking and chronic disease
- actively promote positive lifestyle changes
- make it easier for Aboriginal and Torres Strait Islander people to access smoking-related health services.

In an example, the Midwest region of WA team held community events, used local radio and newspaper and distributed promotional materials to spread the anti-smoking message. The success of the strategy was shown by an increase in calls to the Aboriginal Quitline following the campaign [39, 40].

Broader initiatives that may be helpful in promoting lifestyle changes to address risk factors for cancer include:

- increasing the 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 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 Aboriginal and Torres Strait Islander audiences [40].

Health care

Culture and identity are central to Aboriginal and Torres Strait Islander perceptions of health. Health care services that engage Aboriginal and Torres Strait Islander social and cultural practices can improve health outcomes for these patients [41].

Accordingly, health care providers who understand the beliefs and perspectives of Aboriginal and Torres Strait Islanders about cancer will be better placed to care for patients [11, 42]. There are many cultural awareness training programs available in Australia which aim to educate health professionals about the needs of their Aboriginal and Torres Strait Islander clients.

Key elements of cancer care for Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander Community Controlled Health Services

play a central role in cancer prevention and care and especially in the social, emotional and cultural wellbeing of individuals [43]. Services include; prevention and lifestyle programs; cancer diagnosis, treatment and management; transportation to medical appointments; outreach clinic services; and immunisations.

General practitioners (GPs) can provide diagnosis, referral to specialists, some treatments, psychological and practical support and oversee the patient's transition to survivorship or palliative care. However, data suggests that Aboriginal and Torres Strait Islander people are less likely to visit a GP for cancer related matters than are non-Indigenous people [34, 44].

Secondary and tertiary health professionals, including specialists such as oncologists and surgeons, guide the direction of further investigations, treatment and associated patient care. People affected by cancer may need to see a specialist for regular follow-up after treatment.

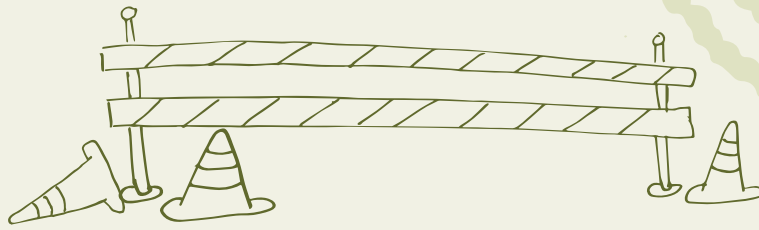
Aboriginal Health Workers (AHWs) can assist patients in their navigation of the health system after a cancer diagnosis in a culturally safe way [45, 46]. In a Queensland study, AHWs were the most commonly used of all hospital services by Aboriginal and Torres Strait Islander patients, highlighting the importance of their role in offering culturally-sensitive support to cancer patients [47].

Integrated Team Care (ITC). The high prevalence of comorbidities (multiple health conditions) among Aboriginal and Torres Strait Islander people means that often cancer care is incorporated into broader care arrangements for a patient [48]. The role of the Care Coordinator (who may be an AHW) can include: advocating on behalf of the patient; ensuring culturally safety; providing health education; encouraging completion of treatment; symptom management; psychosocial care; and referral to local services.

Aboriginal and Torres Strait Islander cancer support groups can improve cancer awareness and increase participation in cancer screening services. For example, Aboriginal women attending such support groups have reported an increased understanding of screening and reported less fear and concern over cultural appropriateness, with increases in screening rates [12]. Support groups have also been found to help in follow up and ongoing care for cancer survivors [48, 49, 50].

Supportive Care Needs Assessment Tool for Indigenous people (SCNAT-IP) is a culturally-specific assessment tool that helps practitioners to understand the supportive care needs of Aboriginal and Torres Strait Islander people with cancer, for example psychological counselling, assistance with travel to tertiary treatment or financial assistance. The tool was developed by Menzies School of Health Research [51].

Telehealth is a strategy for delivering coordinated multidisciplinary care in regional cancer centres. It may be helpful for some patients in facilitating appropriate access to medical specialists not available in their area and some cancer-related services such as teleoncology [52].



Barriers

A number of factors can prevent the early detection of cancer in Aboriginal and Torres Strait Islander people including:

- historic factors such as colonisation (including racism), political and socioeconomic disadvantage which have had flow on effects across generations which can include a lack of trust of healthcare professionals
- difficulty getting to health services, with large distances to travel and poor availability of services in poor availability of services, including cancer services, in remote areas. The larger numbers of Aboriginal and Torres Strait Islander people living in remote areas [15], relative to non-Indigenous people, means that they are particularly disadvantaged
- long waiting periods - 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 [53]
- inadequate numbers of Aboriginal and Torres Strait Islander health professionals and high staff turnover in Indigenous-specific roles and organisations
- lack of understanding of cancer symptoms or a denial of symptoms may result in delays in seeking health care [23].

Further barriers to the use of cancer health services by Aboriginal and Torres Strait Islander people may include:

- costs associated with consultation fees, medicines, transport and lost wages
- poor collaboration between different parts of the health system
- cultural misunderstandings, poor communication and discrimination
- differing cultural beliefs about cancer, including feelings of fear or shame.

Screening programs and services

Screening programs and services are important to help detect cancer early and increase people's awareness of cancer symptoms [12]. Early detection means a person can seek treatment sooner which may improve outcomes. To increase participation in screening programs, it is important they are designed to be culturally sensitive and appropriate to the knowledge, attitudes and beliefs of Aboriginal and Torres Strait Islander people.

Some Government-funded screening programs in Australia are:

BreastScreen Australia

The national breast screening program, BreastScreen Australia, was established in 1991 as the National Program for the Early Detection of Breast Cancer [54]. The program aims to reduce sickness and deaths caused by breast cancer through early detection using screening mammography. The program provides free two-yearly screening mammograms to women aged 40 years and over. The program is run from hospitals, health services and a mobile van that travels to rural and remote locations across Australia.

National Bowel Cancer Screening Program (NBCSP)

In 2006, Australia introduced a formal, government-funded, population-based bowel cancer screening program [55]. The NBCSP aims to reduce sickness and deaths caused by bowel cancer by screening target population groups for early detection of the disease. People aged between 50 and 74 are sent a free bowel screening test kit and asked to send a faecal sample to a pathology laboratory for analysis. The *National Indigenous Bowel Screening Pilot* was developed in response to low Aboriginal and Torres Strait Islander participation in the NBCSP [55]. It provides a coordinated national approach to promote bowel cancer awareness and screening among Aboriginal and Torres Strait Islander people.

National Cervical Screening Program (NCSP)

The *NCSP* was implemented in 1995 to reduce the prevalence of cervical cancer deaths in Australian women [28]. In 2017, major changes to the program were implemented, in particular the Pap test was replaced with the Cervical Screening Test - which is expected to protect up to 30% more women because it detects HPV. Cervical screening is offered to women as part of their primary health care. All women aged 25 to 75 years are prompted to take a cervical screening test every five years (or more frequently if required). A national cancer screening register has been established to support the renewed program.

Participation in screening programs

Across the main national screening programs there are consistently lower rates of participation for Aboriginal and Torres Strait Islander people.



Breast screening participation

Indigenous 37%
Non-Indigenous 53%



Bowel screening participation

Indigenous 20%
Non-Indigenous 43%



Cervical screening participation

Estimated gap of 20%-30% Between non-Indigenous and Indigenous women

In 2014-15, participation of Aboriginal and Torres Strait Islander women in the BreastScreen program was 37% compared with 53% for non-Indigenous women [54]. This level of participation for Aboriginal and Torres Strait Islander women has been consistent for a number of years. The lower survival rate for breast cancer among Aboriginal and Torres Strait Islander women can be partly explained by lower participation in the BreastScreen Australia early detection program [54, 56].

For the National Bowel Cancer Screening Program it was estimated that the participation rate for Aboriginal and Torres Strait Islander people in 2015-2016 was 20%; this compares with an estimated participation rate for non-Indigenous people of 43% [55].

Findings from studies of the National Cervical Screening Program [57, 58] 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%.

There has been criticism in the past, of the way in which cancer screening programs developed for the general population work for the Aboriginal and Torres Strait Islander populations. The need for flexibility in the delivery of screening services has now been acknowledged by many service providers who have developed ways to promote and conduct cancer screening which are culturally appropriate and sensitive.

Breast screening - increasing Aboriginal and Torres Strait Islander participation

BreastScreen liaise closely with AHWs and Aboriginal and Torres Strait Islander community groups to increase participation in screening activities. BreastScreen makes it possible for Aboriginal and Torres Strait Islander women to attend as a group if that is preferred and in some cases allow women to 'drop in' or attend as last minute clients [59]. Many state and territory BreastScreen programs also offer transport to and from screening clinics, another useful strategy to increase participation.

A Queensland project, *Closing the Gap in Breast Cancer Screening*, confirmed that a 'one-size-fits-all' model often does not work for Aboriginal and Torres Strait Islander women [54]. The project addressed barriers to screening for Aboriginal and Torres Strait Islander women through culturally appropriate messages, art shows and partnerships with local groups, in order to build trust, educate and support Aboriginal and Torres Strait Islander women to attend BreastScreen Australia services. The project reported an increase in participation rates from 49% to 56% in two years.

National initiatives to improve cancer care

There are a number of organisations which have initiatives in place aimed at improving cancer care for Aboriginal and Torres Strait Islander people including:

Cancer Australia – works to reduce the impact of cancer on Aboriginal and Torres Strait Islander people by [60]:

- raising awareness of risk factors
- developing evidence-based information and resources for Aboriginal and Torres Strait Islander people affected by cancer, such as *My Lung Cancer Pathway* [61]
- providing cancer information and training resources to Aboriginal and Torres Strait Islander Health Workers.

Cancer Council Australia and the Cancer Councils in each state – provide information and resources tailored to Aboriginal and Torres Strait Islander patients and health workers and run community activities such as [62]:

- detection and prevention programs
- cancer research grants
- cancer support groups, services and programs.

National Indigenous Cancer Network (NiCAN) – established to improve outcomes for Indigenous people with cancer, including their carers, families and communities:

- bringing together Indigenous audiences, cancer survivors, service providers, researchers and health professionals, the private sector and government organisations.

Breast Cancer Network Australia – the peak national organisation for those affected by breast cancer supports, informs, represents and connects people affected by breast cancer:

- working with governments and health service providers to make sure all Australians are able to get affordable access to the latest breast cancer treatment and care [63].

Policies and strategies

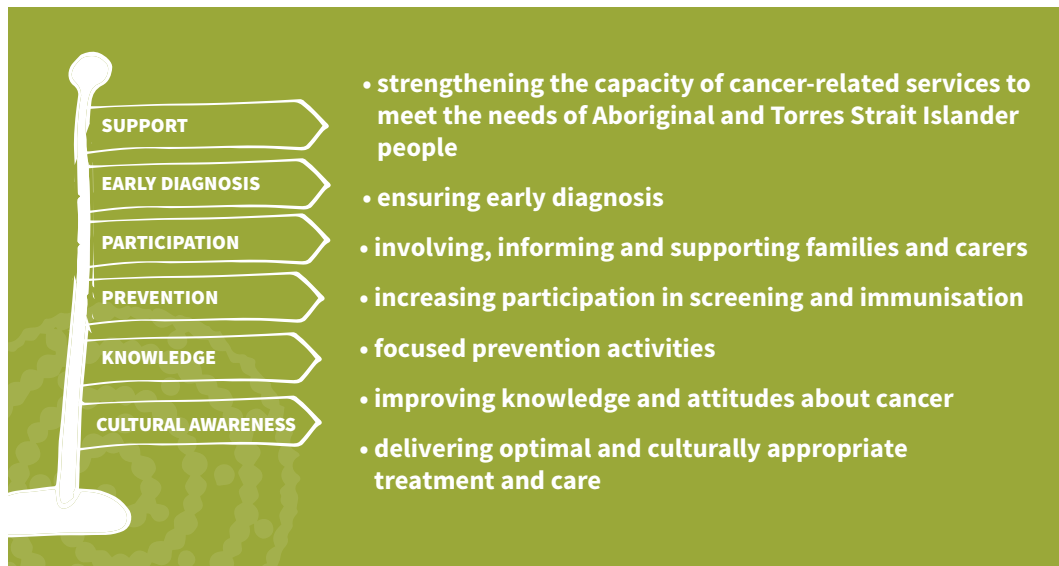


The first national strategy to improve cancer outcomes for Aboriginal and Torres Strait Islander people, the *National Aboriginal and Torres Strait Islander Cancer Framework* (the *Framework*) [64], was released in 2015. It provides guidance for individuals, communities, organisations and governments. The *Framework* covers all aspects cancer including prevention, screening and early detection, diagnosis and treatment, palliative care and survivorship, as well as the policies, research and infrastructure that surround those service areas. It sets out priority areas for action, and allows flexibility for communities and organisations to work in ways that suit their local context and local needs. Health professionals working with Aboriginal and Torres Strait Islander people as well as individuals affected by cancer were involved in the development of the *Framework*.

In 2018, Cancer Australia released the *Optimal care pathway for Aboriginal and Torres Strait Islander people* [48] which recommended new approaches to cancer care specifically for Aboriginal and Torres Strait Islander people with cancer. It shows health services and health professionals how to make sure services are culturally safe and responsive to the needs of Aboriginal and Torres Strait Islander people. A series of resources for patients were also published. They outline what patients should expect on the cancer pathway, from tests and diagnosis, through to treatment and care, management of cancer that has spread, and end-of-life care.

Future directions

Some suggestions for future research and action based on the National Aboriginal and Torres Strait Islander Cancer Framework [64] include:



Additionally, there is a significant need for improved local, state and national data on Aboriginal and Torres Strait Islander people with cancer [64-67]. Quality data are critical to understanding the variations in cancer care and outcomes for Aboriginal and Torres Strait Islander people, and to inform policy, service provision and clinical practice initiatives to improve those outcomes.

Concluding comments

This summary describes cancer among Aboriginal and Torres Strait Islander people in Australia – its extent, the main risk factors, prevention and care, and national programs and initiatives in place to reduce its impact for individuals and communities. Despite 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. This is highlighted by statistics which show that, despite lower rates of prevalence and hospitalisation Aboriginal and Torres Strait Islander people experience higher rates of cancer deaths compared to non-Indigenous people.

Reducing the impact of cancer among Aboriginal and Torres Strait Islander people is an important aspect in ‘closing the gap’ in health outcomes. The summary highlights the need to address barriers for Aboriginal and Torres Strait Islander people to accessing and utilising screening and other health services. Strategies and initiatives should ensure community ownership and self-determination of the overall health and wellbeing of communities.

The HealthInfoNet cancer portal includes a library of more than 1,000 publications, over 200 resources and 100 programs relating to cancer among Aboriginal and Torres Strait Islander people.

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