

**Cancer Australia**

**NATIONAL  
ABORIGINAL AND  
TORRES STRAIT ISLANDER  
CANCER FRAMEWORK  
2015**



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ISBN Print: 978-1-74127-296-2 Online: 978-1-74127-294-9

**Recommended citation**

Cancer Australia, 2015. *National Aboriginal and Torres Strait Islander Cancer Framework*, Cancer Australia, Surry Hills, NSW.

*National Aboriginal and Torres Strait Islander Cancer Framework* can be downloaded from the Cancer Australia website: [canceraustralia.gov.au](http://canceraustralia.gov.au).

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# Contents



Statement of acknowledgement.....	2
Foreword .....	3
Purpose.....	4
Aim.....	4
Context.....	4
Development of this Framework.....	8
Principles.....	9
Priorities.....	10
Priority 1.....	11
Priority 2 .....	12
Priority 3 .....	13
Priority 4.....	14
Priority 5 .....	15
Priority 6.....	18
Priority 7 .....	19
Acknowledgements .....	21
Thanks and appreciation.....	22
Glossary .....	24
References.....	26



## Statement of acknowledgement

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We acknowledge the traditional owners of country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present. We would like to thank Aboriginal and Torres Strait Islander people for their contributions, without which this National Aboriginal and Torres Strait Islander Cancer Framework would not have been possible.

Cancer Australia acknowledges that there is no single Australian Aboriginal and Torres Strait Islander culture or group and that there are many diverse communities, language groups and kinships throughout Australia. However, when presenting data we will be respectfully using the term Indigenous Australians.



# Foreword from the Minister



In many respects, the Australian health system is the envy of the world. Australian people enjoy universal access to high quality health care and subsidised medicines. The benefits of this system are evidenced by continual improvements to life expectancy and other measures such as cancer mortality rates.

Unfortunately, like many other critical health measures, improvements in cancer survival rates have not been enjoyed to the same extent by Aboriginal and Torres Strait Islander peoples.

Alarming, the cancer mortality gap between Indigenous Australians and non-Indigenous Australians has grown. Without appropriate action, that gap is likely to grow further.

Between 1998 and 2012, the cancer mortality rate for non-Indigenous Australians fell by 10%. During this same period, the cancer mortality rate for Indigenous Australians increased by 16%. These results are as confronting as they are disturbing.

Aboriginal and Torres Strait Islander people also continue to face significantly higher risk factors for cancer. For instance, the smoking rate for non-Indigenous Australians aged 14 and over currently sits at 12.8%. By contrast, the smoking rate for Indigenous Australians aged 15 and over is more than 40%. If we can reduce risk factors like this, the unacceptable disparities in cancer mortality rates will improve.

This Framework provides strategic direction in cancer control to reduce the unwarranted variations in Aboriginal and Torres Strait Islander cancer outcomes. With time and commitment, the implementation of this Framework will reduce disparities and improve outcomes for Indigenous Australians with cancer.

I commend the work of Cancer Australia and Menzies School of Health Research as well as the many organisations and individuals from around the country who contributed to the development of this Framework. Their combined knowledge, expertise and commitment to take this Framework forward will maximise outcomes for Aboriginal and Torres Strait Islander cancer control efforts across the health sector.

Signed,

A handwritten signature in black ink, appearing to read 'Sussan Ley'. The signature is fluid and cursive.

The Hon Sussan Ley MP  
Minister for Health  
Minister for Sport

## Purpose

The National Aboriginal and Torres Strait Islander Cancer Framework (the Framework) provides high-level guidance and direction for the many individuals, communities, organisations and governments whose combined efforts are required to address disparities and improve cancer outcomes for Aboriginal and Torres Strait Islander peoples.

This Framework is designed to complement and enhance national, jurisdictional, regional and local efforts to improve Aboriginal and Torres Strait Islander cancer outcomes, including cancer plans and related policies, frameworks and action plans. It sets out priority areas for action, and allows the flexibility for jurisdictions, communities and organisations to address those priorities in ways that suit their local context and local needs.

This Framework encompasses the full continuum of cancer control, including cancer prevention, screening and early detection, diagnosis and treatment, palliative care and survivorship; and the policy, systems, research and infrastructure that surround these service areas.

## Aim

By providing this direction and identifying the priorities that most require attention, this Framework aims to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples by ensuring timely access to good quality and appropriate cancer related services across the cancer continuum.

## Context

### **Cancer among Aboriginal and Torres Strait Islander peoples**

Australia's record of cancer survival is one of the best in the world, yet Aboriginal and Torres Strait Islander people continue to experience disparities in cancer outcomes. Cancer is the second most common cause of death for Indigenous Australians (20%), after cardiovascular disease.<sup>1</sup>

Aboriginal and Torres Strait Islander people:

- have a different pattern of cancer incidence, with some cancers occurring more commonly than amongst non-Indigenous Australians (lung, liver, cervical cancers), while other cancers occur at lower incidence rates (prostate, bowel, breast cancer among women)<sup>2</sup>
- have high incidence of cancers that are preventable but are also more likely to be fatal (lung cancer, liver cancer)<sup>2</sup>

- have higher levels of modifiable risk factors relevant to cancer including smoking, risky alcohol consumption, poor diet, low levels of physical activity and high levels of infection such as Hepatitis B<sup>3</sup>
- are less likely to participate in cancer screening programs<sup>3</sup>
- are more likely than other Australians to be diagnosed when cancer is at an advanced stage of development<sup>4</sup>
- are less likely to receive adequate treatment or be hospitalised for cancer<sup>1</sup>
- have a slightly lower rate of cancer diagnosis but a 30% higher mortality rate than non-Indigenous Australians (221 and 172 per 100,000 respectively, age standardised mortality)<sup>2</sup>
- have had a significant increase in the mortality rate due to cancer (16% between 1998 and 2012) while the cancer mortality rate for non-Indigenous people has fallen significantly (10% over the same period).<sup>1</sup> This means the Indigenous to non-Indigenous mortality gap due to cancer is likely to continue to grow
- are much less likely to survive five years after a diagnosis of cancer than non-Indigenous Australians. This difference is greatest within the first year following diagnosis. On average, 74% of non-Indigenous Australians will survive for one year beyond a cancer diagnosis, but only 61% of Aboriginal and Torres Strait Islander people will survive for the same length of time<sup>3</sup>
- face significant burden of disease, with cancer being the second leading cause of fatal burden of disease for Indigenous Australians.<sup>5</sup>

Smoking rates amongst Aboriginal and Torres Strait Islander people, although improving, remain higher than in the broader Australian population, and smoking remains a major cause of cancer.<sup>3</sup> Lung cancer remains the major cause of death from cancer for Aboriginal and Torres Strait Islander and, along with other smoking related cancers, makes up a large proportion of the cancer burden.<sup>3</sup>

Aboriginal and Torres Strait Islander people also have high levels of a number of other risk factors for cancer, including obesity, lack of exercise, risky levels of alcohol consumption and hepatitis infections.<sup>3</sup>

The most common cancers among Aboriginal and Torres Strait Islander people after lung cancer are breast cancer (among women), bowel cancer and prostate cancer.<sup>2</sup>

## Defining good quality cancer care

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Increasingly, definitions of ‘quality’ in cancer care have broadened to extend beyond the clinical treatment of disease.<sup>6,7</sup> A range of contextual factors can impact on the uptake of treatment and engagement with cancer control activities across the continuum of care, and are therefore important to recognise within the concept of quality in cancer care.

Within the context of improving the cancer outcomes of Aboriginal and Torres Strait Islander peoples, ‘quality cancer care’ is defined within this Framework as care that:

- is based on the best available evidence or good practice guidelines with regard to effectiveness, safety and impact (taking into consideration contextual factors including age, co-morbidity, quality of life and patient preferences and choices)
- is person centered so that the whole person (including family and cultural role) is considered, and the psychosocial, cultural and supportive care needs and preferences of Aboriginal and Torres Strait Islander people are addressed across the continuum of care<sup>8</sup>
- is multidisciplinary and integrated across health sectors (primary, secondary and tertiary care) and into the community (including referral pathways to primary care, allied health and other relevant community services)<sup>9</sup>
- incorporates quality improvement processes for ongoing assessment, review, evaluation and improvement of care<sup>6,10</sup>
- includes strong involvement and leadership from Aboriginal and Torres Strait Islander people (including those affected by cancer) to ensure care is effective and appropriate to their needs and preferences<sup>10</sup>
- occurs in a timely and equitable manner, and delivers best practice care as close to home as (safely) possible<sup>11,12</sup>
- is delivered by skilled and caring staff with effective cross-cultural communication skills, supported by organisations in which cultural competence is embedded as integral to quality and safety.<sup>6,10</sup>



# Concepts fundamental to Aboriginal and Torres Strait Islander health

Key concepts which are fundamental to Aboriginal and Torres Strait Islander health, including cancer control, have been considered in the development of this Framework.

## **A holistic approach to health and wellbeing**

Aboriginal and Torres Strait Islander concepts of health extend beyond the physical wellbeing of an individual to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being.<sup>13</sup>

## **The diversity of Aboriginal and Torres Strait Islander peoples**

Aboriginal and Torres Strait Islander people and communities are diverse, including across gender, age, language, geographic location, sexual orientation, religious beliefs, family responsibilities, marriage status, life and work experiences, personality and educational levels.<sup>14</sup>

## **The social and cultural determinants of health**

Aboriginal and Torres Strait Islander health is significantly affected by the social and cultural determinants of health. Aspects of the broader social environment that can influence (in a negative or positive way) the capacity of individuals, families and communities to engage with health care and manage their own health.<sup>15</sup> For Aboriginal and Torres Strait Islander people, the social and cultural determinants of health may include support from family, community and church groups, connection to culture and country, a sense of empowerment or self-efficacy, education and literacy levels, poverty, marginalisation from the dominant culture, racism, poor housing, poor nutrition, smoking and other high risk behaviours, and living in remote areas.<sup>16-20</sup>

# Development of this Framework

This National Aboriginal and Torres Strait Islander Cancer Framework was developed by Cancer Australia in partnership with Menzies School of Health Research. The project was overseen by a Project Steering Group, which had a majority of Aboriginal and Torres Strait Islander members.

## The development of this Framework was informed by two major strands of work:

### 1. A review of the evidence

A systematic literature review of qualitative and quantitative evidence was conducted to examine the issues, gaps and priorities for improving cancer outcomes in Aboriginal and Torres Strait Islander peoples. This included population health data on Aboriginal and Torres Strait Islander peoples, papers from peer-reviewed scientific journals and unpublished (or 'grey') literature. The review provided the evidence base which informed the structure for the stakeholder consultations and development of this Framework.

### 2. Stakeholder consultations

A range of consultative approaches were used to reach stakeholders across Australia, in order to maximise engagement in the development of this Framework. These approaches included six face-to-face forums in locations across Australia in urban, regional and remote settings, a widely circulated online survey and online discussion boards.

#### Key stakeholder groups targeted included:

- Aboriginal and Torres Strait Islander people affected by cancer, their families and carers, community leaders and advocates within communities
- Health professionals and service providers who work with Aboriginal and Torres Strait Islander people in cancer control, prevention, diagnosis and treatment, including the community controlled health sector
- Indigenous and non-Indigenous peak professional bodies and associations
- Non-government organisations, researchers, state and territory governments and Commonwealth departments.

Several hundred people from across Australia provided input into the development of this Framework via these consultations. A high proportion of participants were Aboriginal and Torres Strait Islander people, including many directly affected by cancer, their families and carers.

# Principles

This Framework is underpinned by the following principles:

## 1 Aboriginal and Torres Strait Islander people are engaged and involved throughout the planning, design and delivery of cancer services

Evidence shows that services and programs for Aboriginal and Torres Strait Islander people are most likely to be effective when Aboriginal and Torres Strait Islander people are integrally involved throughout the process of development and implementation.<sup>19,21</sup> This applies to services across the cancer continuum including prevention, screening programs and early detection, diagnosis and treatment, supportive and palliative care, and survivorship programs; as well as the physical infrastructure and environments in which services are provided.

## 2 Patients, families, carers and communities are informed and empowered

Aboriginal and Torres Strait Islander patients, families, carers and communities are entitled to have the opportunity and capacity to make well informed decisions about cancer and cancer care, and to feel that their views and decisions will be listened to respectfully.<sup>6,22</sup>

## 3 Working together towards a common goal

Improving the cancer outcomes of Aboriginal and Torres Strait Islander peoples is a shared responsibility. It is a responsibility shared between Aboriginal and Torres Strait Islander people, communities and organisations and the broader health system and health workforce. Achieving change in a complex health system requires action across multiple levels of the health system,<sup>23,24</sup> by numerous independent organisations, communities and individuals, working towards a common goal (in this case, improving the cancer outcomes of Aboriginal and Torres Strait Islander peoples). Shared leadership and robust partnerships are needed to ensure that there is clarity of the goal and effective strategies for achieving it, while still ensuring the flexibility for jurisdictions, communities and organisations to address the goal in ways that suit their local context and local needs.

## 4 Policy and practice informed by reliable data and evidence about what works

Improving the care and experience of people affected by cancer requires: timely access to relevant information about patient needs, progress and outcomes; evidence-based clinical and service guidelines; and data about the extent to which those guidelines are being applied.<sup>6</sup> Policy and practice relevant evidence, and service data are crucial to strengthening the quality of services across the cancer continuum to guide policy and improve practice, and to build an efficient and sustainable cancer control system.

# Priorities



To realise our aim the following priorities should be addressed:

- 1** Improve knowledge, attitudes and understanding of cancer by individuals, families, carers and community members (across the continuum)  
.....
- 2** Focus prevention activities to address specific barriers and enablers to minimise cancer risk for Aboriginal and Torres Strait Islander peoples  
.....
- 3** Increase access to and participation in cancer screening and immunisation for the prevention and early detection of cancers  
.....
- 4** Ensure early diagnosis of symptomatic cancers  
.....
- 5** Ensure Aboriginal and Torres Strait Islander people affected by cancer receive optimal and culturally appropriate treatment, services, and supportive and palliative care  
.....
- 6** Ensure families and carers of Aboriginal and Torres Strait Islander people with cancer are involved, informed, supported and enabled throughout the cancer experience  
.....
- 7** Strengthen the capacity of cancer related services and systems to deliver good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander people.  
.....

## Addressing the priorities for action

The next section provides an overview of each priority and presents enablers that may help in planning or reviewing strategies to address each of the priority areas for action.

# Priority

1

## Improve knowledge, attitudes and understanding of cancer by individuals, families, carers and community members (across the continuum)

The evidence review and consultations reaffirmed the findings of earlier reports<sup>10, 29</sup> that a widespread lack of knowledge about cancer, its causes and symptoms, treatments and likely survivability is a significant barrier to improving the cancer outcomes of Aboriginal and Torres Strait Islander people. Across all three forms of consultation, Aboriginal and Torres Strait Islander people emphasised the benefit of community based action, engagement and empowerment to help build understanding about cancer and increase support for those affected by cancer, their families and carers.

### Enablers

- Enhance community capacity to promote cancer literacy and to support Aboriginal and Torres Strait Islander people affected by cancer.
- Engage and support key community people (survivors, leaders, champions and peer support groups) to promote cancer literacy and share their lived experiences about cancer to reduce misconceptions.
- Ensure community involvement throughout the development of public awareness and health promotion campaigns.
- Use evidence-based public awareness programs and health promotion strategies that specifically address the concerns and needs of Aboriginal and Torres Strait Islander people at particular points along the cancer continuum (e.g. broad community requires general knowledge about cancer, symptoms, survivability, screening; those diagnosed or supporting those affected by cancer require more specific knowledge).
- Ensure that information is available and accessible to Aboriginal and Torres Strait Islander people across the cancer continuum, in formats and language/s that are culturally appropriate.
- Recognise that gender specific strategies may be needed, depending on local context.
- Enable community based primary health services to deliver cancer related health advice in a culturally safe environment to encourage Aboriginal and Torres Strait Islander patients and their families to ask questions, seek further information and return for follow up if required.
- Make cancer awareness and educational opportunities available and accessible to Aboriginal and Torres Strait Islander communities broadly, as well as Indigenous and non-Indigenous health professionals (e.g. by adapting existing accredited Aboriginal and Torres Strait Islander cancer education modules).
- Promote cancer literacy through broader forums (e.g. at community or school events, other chronic disease and health related events) and through other sectors such as the arts or sports.

# Priority 2



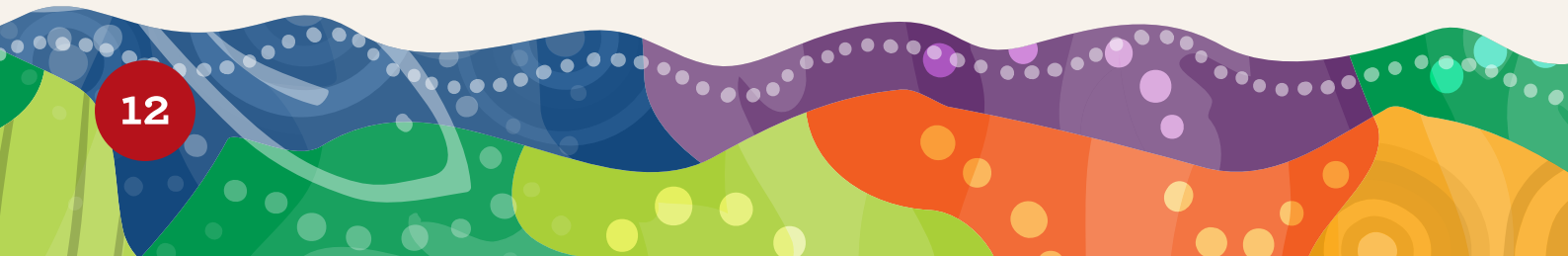
## Focus prevention activities to address specific barriers and enablers to minimise cancer risk for Aboriginal and Torres Strait Islander peoples

Smoking is the major risk factor for cancer among Aboriginal and Torres Strait Islander people; with 42% of Aboriginal and Torres Strait Islander people aged 15 years and older are still smoking on a daily basis<sup>1</sup> and smoking related cancers make up the majority of cancers affecting Aboriginal and Torres Strait Islander people.<sup>26</sup> The high prevalence of smoking and other risk factors including risky levels of alcohol consumption, obesity, poor nutrition, low levels of physical activity and chronic infections such as Hepatitis B, could contribute to the higher cancer mortality rates observed in this population group.<sup>3</sup>



### Enablers

- Use evidence-based, best practice public awareness programs, health promotion and other strategies that address the specific concerns and needs of Aboriginal and Torres Strait Islander people; developed by or with Aboriginal and Torres Strait Islander people.
- Ensure public awareness programs, health promotion and other strategies take into account: the impact of social and cultural determinants of health; place-based approaches suited to local contexts; and the concerns and needs of sub-groups such as men and youth.
- Maintain national, jurisdictional and community momentum on tobacco control and increase attention on other key risk factors including physical inactivity and obesity, chronic infections and alcohol consumption.
- Facilitate the integration of cancer prevention activity, including screening and immunisation, within primary health care and other chronic condition prevention activities (e.g. healthy living programs, and adult health checks), taking into account existing workforce and organisational capacity.
- Focus prevention funding on ongoing programs to sustain the impact of prevention activities.
- Ensure Aboriginal and Torres Strait Islander Health Workers, nurses and other Indigenous and non-Indigenous health professionals, are skilled and enabled to deliver key cancer prevention messages to Aboriginal and Torres Strait Islander people.
- Adopt a systems level approach which utilises a range of strategies, including education and public awareness, legislative and regulatory reforms that support prevention activities and reduce cancer risk.



# Priority 3



## Increase access to and participation in cancer screening and immunisation for the prevention and early detection of cancers

Many potentially preventable or screen-detectable cancers are more common among Indigenous Australians than non-Indigenous Australians,<sup>27</sup> including cancers associated with chronic infections such as Hepatitis B and Human Papilloma Virus (HPV). Indigenous Australians have lower participation in screening programs than non-Indigenous Australians.<sup>3</sup> It is likely that lower participation by Aboriginal and Torres Strait Islander people in cancer screening programs contributes to the high incidence of preventable cancers (such as cervical cancer), and survival of cancers where early detection can significantly improve outcomes (such as bowel, breast and cervical cancers).<sup>26</sup>



### Enablers

- Increase Aboriginal and Torres Strait Islander peoples' involvement with screening programs and in planning and delivery of local screening and early detection activities (e.g. employ Aboriginal and Torres Strait Islander staff; develop partnerships between screening programs and primary health care or other community based services).
- Strengthen community capacity to increase cancer literacy and encourage participation in screening and immunisation, including through key Aboriginal and Torres Strait Islander community members, cancer survivors, champions and Health Workers.
- Ensure regular primary health care checks include discussion and reminders about screening.
- Increase access to screening services by addressing barriers by making screening services less confronting or alienating and more culturally appropriate, including through gender appropriate screening facilities, staff and approaches.
- Ensure follow up of abnormal results in ways that facilitate timely diagnosis and treatment if required.
- Promote quality improvement initiatives that encourage screening and primary health care services to use their own data, including client feedback, to inform planning and improve the quality of screening services for Aboriginal and Torres Strait Islander people.
- Identify and address barriers to participation in screening or early detection activities for specific groups or cancer types (e.g. men and bowel cancer screening).
- Increase the capacity of Indigenous and non-Indigenous health professionals to discuss screening and immunisation with Aboriginal and Torres Strait Islander people.



# Priority 4



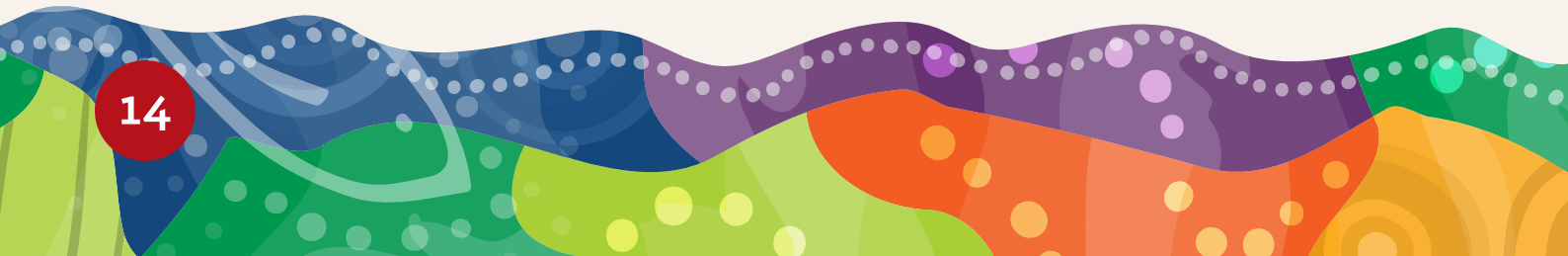
## Ensure early diagnosis of symptomatic cancers

Indigenous Australians are more likely to be diagnosed with cancer that has progressed to an advanced stage than non-Indigenous Australians<sup>4,8</sup>, and this may contribute to higher mortality. Barriers to timely diagnosis include comorbidities masking cancer symptoms; lack of knowledge about cancer, its symptoms and survivability amongst Aboriginal and Torres Strait Islander communities; fear (of the potential effects of treatment, of having to spend lengthy periods away from family and country undergoing treatment) and the general barriers that Aboriginal and Torres Strait Islander people may experience in accessing health services.<sup>10</sup>



### Enablers

- Improve knowledge about cancer symptoms and the benefits of early detection (for both community members and health workforce).
- Increase engagement of Aboriginal and Torres Strait Islander people with primary health care by addressing barriers to access, fears of cultural alienation and limited health literacy; expanding the Aboriginal and Torres Strait Islander health workforce.
- Increase access to diagnostic services, particularly in rural and remote areas.
- Support all health professionals working with Aboriginal and Torres Strait Islander patients to apply culturally safe approaches to discussing diagnosis, treatment and other aspects of cancer care.
- Follow or establish agreed appropriate referral pathways that are known and supported by practitioners (including Aboriginal and Torres Strait Islander Health Workers and nurses).
- Increase awareness amongst primary health care practitioners of Aboriginal and Torres Strait Islander cancer as a priority, the potential for comorbidities to mask symptoms, and increase integration of cancer within chronic disease programs.
- Identify opportunities to strengthen connections between cancer specific services and primary health care services.





# Priority 5



## Ensure Aboriginal and Torres Strait Islander people affected by cancer receive optimal and culturally appropriate treatment, services, and supportive and palliative care

Culturally safe services and a culturally competent workforce that is able to address the needs of Aboriginal and Torres Strait Islander people are core requirements for improving cancer outcomes. Increased use of multidisciplinary care teams that include cultural as well as clinical expertise could support culturally appropriate quality cancer care, particularly in rural and remote areas. Late diagnosis of cancer may mean that treatment options are greatly limited or more complex. Treatment options may also be compromised by comorbidities. However, Indigenous Australians are likely to receive less active treatment for cancer than non-Indigenous Australians, even after controlling for comorbidities.<sup>7</sup> The reasons for lower treatment rates are not clear.

5a

### Ensure a skilled and caring workforce with effective cross-cultural communication skills



#### Enablers

- Expand opportunities for the Aboriginal and Torres Strait Islander health workforce to work across the cancer continuum within cancer related services.
- Ensure the Aboriginal and Torres Strait Islander health workforce is supported through ongoing opportunities for professional development that are accessible and lead to better quality of care.
- Embed cultural competence as an integral part of quality and safety programs for cancer related services and development programs for health professionals.
- Develop and use protocols, decision or communication aids to enhance effective communication between clinicians and Aboriginal and Torres Strait Islander people with cancer, their families and carers.
- Increase the availability of interpreters for Aboriginal and Torres Strait Islander languages where appropriate.
- Ensure that all health professionals working with Aboriginal and Torres Strait Islander patients have adequate training and skills in delivering culturally safe health care and medical advice.



- Ensure that training is standardised, ongoing and accessible to all areas of cancer related services including accommodation facilities and psychosocial support services.
- Ensure that all health professionals are trained, skilled and/or have appropriate communication aids available to talk with patients, families and carers about consent for care.
- Use multidisciplinary care teams, including cultural as well as clinical expertise, to support culturally appropriate cancer care for Aboriginal and Torres Strait Islander peoples, particularly in rural and remote areas.
- Improve availability of Aboriginal and Torres Strait Islander Health Workers, hospital liaison officers and cancer coordinators (with both clinical and community knowledge) to actively assist patients, families and carers to navigate the system and access services.

5b

**Ensure Aboriginal and Torres Strait Islander people receive best practice care**

**Enablers**

- Establish and follow agreed and appropriate referral pathways (including referral to supportive and palliative care) that are known and supported by practitioners (including Aboriginal and Torres Strait Islander Health Workers and nurses).
- Understand and address barriers to accessing cancer services (including those between public and private systems).
- Ensure practice and service guidelines are designed and implemented with consideration of best practice cancer care for Aboriginal and Torres Strait Islander people.
- Ensure active follow up of Aboriginal and Torres Strait Islander people with cancer, preferably carried out by an Aboriginal or Torres Strait Islander person, immediately after diagnosis and throughout their cancer journey.
- Identify the supportive care needs of Aboriginal and Torres Strait Islander patients and families (including youth and children) at time of diagnosis and throughout the rest of the cancer continuum through the use of culturally relevant validated tools as part of routine practice.
- Ensure access to supportive care services tailored to the specific social, practical, and cultural needs of Aboriginal and Torres Strait Islander people and families, including children.
- Ensure that Aboriginal and Torres Strait Islander people affected by cancer are aware of the availability of these supportive care services across the cancer continuum.
- Ensure psychosocial care needs, including social, emotional, spiritual and cultural wellbeing are explicitly considered in the identification of cancer care needs.
- Provide 'right place' cancer care as close to home as (safely) possible. Less complex aspects of care can be delivered closer to home, particularly as modern technologies make it more feasible to link experts into multidisciplinary care teams over distance.

- Extend the safe use of innovative approaches, such as telemedicine, to minimise the need to travel for care.
- Ensure that travel schemes and accommodation arrangements meet the unique needs of Aboriginal and Torres Strait Islander people, including cultural obligations, and facilitate access to, and completion of, treatment or other aspects of care (across the whole cancer continuum).
- Provide information that addresses the concerns and needs of Aboriginal and Torres Strait Islander people across the cancer continuum, in formats and language/s that are accessible and culturally appropriate.
- Increase understanding of, and address barriers to, access and use of palliative care services by Aboriginal and Torres Strait Islander people.
- Encourage cross-sector organisations (such as charities and consumer support organisations) to better meet the needs of Aboriginal and Torres Strait Islander people with cancer, their families and carers.



# Priority **6**



## **Ensure families and carers of Aboriginal and Torres Strait Islander people with cancer are involved, informed, supported and enabled throughout the cancer experience**

Families and carers provide critical support to Aboriginal and Torres Strait Islander people affected by cancer and they themselves may need support to ensure they can effectively assist with their loved one's cancer experience. Families and carers often play a significant role in a patient's cancer experience by providing emotional, social or financial support, and assist in communication between the patient and health professionals. Families and carers should have access to information and supportive care services to ensure that they can continue supporting their loved ones.<sup>9</sup>



### **Enablers**

- Identify and appropriately incorporate the role of families and carers in supporting Aboriginal and Torres Strait Islander people with cancer.
- Ensure that the psychosocial and practical needs of families and carers are identified and addressed from the point of diagnosis, throughout treatment and in the transition to survivorship, or into palliative care and beyond the end of life stage.
- Ensure that families and carers have access to the information and services they need to appropriately support and advocate for the person diagnosed with cancer.
- Build the capacity of Aboriginal and Torres Strait Islander Health Workers, nurses, counsellors and other health professionals to provide appropriate cancer information and support, including to families with young children with cancer.
- Ensure access to interpreters for Aboriginal and Torres Strait Islander people with cancer, their families and carers.



# Priority 7



## Strengthen the capacity of cancer related services and systems to deliver good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander people

Quality national, jurisdictional and local data are critical to understanding the variations in cancer care and outcomes of Aboriginal and Torres Strait Islander people. Currently there is limited evidence or data available to inform policy, health promotion, service provision and clinical practice initiatives to improve outcomes for Aboriginal and Torres Strait Islander peoples. There is no national data on stage at diagnosis and treatments received. Integrated pathways between various services are required to strengthen the consistency and quality of care. This is facilitated through good system infrastructure, including comprehensive data capture, timely information transfer and defined protocols and standards. Additionally, targeted and prioritised research is required.

### 7a

#### Enhance data systems to inform better outcomes



#### Enablers

- Establish data systems that facilitate coordinated and multidisciplinary care across jurisdictions, levels of care (primary, tertiary), and in which the patient history is tracked.
- Promote collection and analysis of Aboriginal and Torres Strait Islander patient, family and carer perceptions of their cancer care experience.
- Improve the identification and recording of Indigenous status, including on pathology requests and reports.
- Support the consistent reporting and analysis of national data on cancer stage at diagnosis.
- Support routine national data collection, access and linkage to allow national monitoring, reporting and inform strategies to improve cancer outcomes.
- Link incidence data to treatment data, to provide a system-wide indication of patterns of care and of time between diagnosis and access to treatment.
- Use quality improvement processes to assess, inform and improve the extent to which cancer services address the needs and preferences of the Aboriginal and Torres Strait Islander people who use them.



7b

**Targeted and priority research to inform policy, health promotion, service provision and clinical practice**

**Enablers**

- Recognise Aboriginal and Torres Strait Islander cancer as a research priority.
- Undertake research that produces evidence about the effectiveness of strategies to improve the cancer outcomes of Aboriginal and Torres Strait Islander peoples to inform policy, practice and service delivery.
- Promote systematic evaluation of programs and services to build a more robust evidence base including through internally driven activities such as quality improvement activities.
- Ensure that priorities for research and evaluation are informed by areas of need, and are identified and supported by Aboriginal and Torres Strait Islander communities.
- Ensure that research is designed, conducted and reported with a focus on translation into policy and practice, and communicated in plain language to relevant audiences and particularly to Aboriginal and Torres Strait Islander communities involved.
- Research and evaluation processes should be designed and conducted with Aboriginal and Torres Strait Islander people throughout.

# Acknowledgements



The National Aboriginal and Torres Strait Islander Cancer Framework has been developed to inform the work of Cancer Australia and for use by Aboriginal and Torres Strait Islander communities, the Aboriginal community controlled health sector, health professionals and service providers, cancer control organisations, researchers and policy makers within governments.

This Framework has been informed by a review of the available evidence and by listening to the voices of Aboriginal and Torres Strait Islander people with a lived experience of cancer, and the expertise and experience of people working in Aboriginal and Torres Strait Islander cancer control.

Cancer Australia is encouraged by the level of engagement expressed by over 500 individuals who contributed to this Framework's development. This included Aboriginal and Torres Strait Islander people who have been affected by cancer, their families and carers; community leaders and members; health professionals; service providers; organisations with a cancer control interest; and policy makers and researchers. Cancer Australia would like to thank these individuals for sharing their lived experiences and expertise.

The national priorities identified in this Framework should guide future directions in Aboriginal and Torres Strait Islander cancer control at all levels in order to address the unwarranted variations in cancer outcomes experienced by Aboriginal and Torres Strait Islander peoples.

Cancer Australia gratefully acknowledges the leadership of the Project Steering Group who provided high level expert advice and guidance throughout the development of the National Aboriginal and Torres Strait Islander Cancer Framework.

**Professor Jacinta Elston (Chair)**, James Cook University

**Dr Jason Agostino**, National Aboriginal Community Controlled Health Organisation

**Dr Siddhartha Baxi**, South West Radiation Oncology Centre

**Professor Tom Calma AO**, Consultant to the Commonwealth Department of Health

**Ms Liela Murison**, Townsville Cancer Centre

**Professor David Roder**, University of South Australia

**Ms Dawn Ross**, Consumer Representative

**Associate Professor Sabe Sabesan**, Townsville Cancer Centre

**Ms Violet Sheridan**, Consumer Representative

**Mr Rajah Supramaniam**, Cancer Council NSW

**Ms Meredith Taylor**, Commonwealth Department of Health

**Professor Helen Zorbas AO**, Cancer Australia

We also acknowledge the significant contributions of Menzies School of Health Research, Associate Professor Gail Garvey, Ms Jenny Brands and Ms Bridget Kehoe who undertook the development of the Framework with Cancer Australia.

Cancer Australia staff in the Indigenous and Rural Program who oversaw the development and preparation of the Framework were Ms Jennifer Chynoweth, Ms Isabella Wallington, Ms Lauren Kinsella and Ms Samantha Webster.

# Thanks and appreciation

Cancer Australia would like to sincerely thank the following organisations who participated in the development of the Framework.

Aboriginal Health and Medical Research Council of New South Wales

Aboriginal Health Council of South Australia

Aboriginal Health Council of Western Australia

Aboriginal Medical Services Alliance Northern Territory

Australian Bureau of Statistics

Australian Catholic University

Australian Indigenous Doctors' Association

Australian Indigenous HealthInfoNet

Australian Institute of Health and Welfare

Aboriginal Medical Service Western Sydney

Australian Women's Health Network

Ballarat Health Services

Breast Cancer Network Australia

BreastScreen VIC

BreastScreen QLD

BreastScreen WA

Bowel Cancer Australia

Bupa Health insurance

Cancer Council ACT

Cancer Council Australia

Cancer Council NSW

Cancer Council NT

Cancer Council QLD

Cancer Council SA

Cancer Council VIC

Cancer Council WA

Cancer Institute NSW

Cancer Nurses Society of Australia

Cancer Voices Australia

CanSpeak

CanTeen

Calvary Mater Newcastle

Charles Darwin University

Congress of Aboriginal and Torres Strait Islander Nurses and Midwives

Department of Health

Department of Health ACT

Department of Health and Human Services VIC

Department of Health NT

Department of Health NSW

Department of Health QLD

Department of Health WA

Department of Health SA

Far North Queensland Medicare Local

Flinders University

Geraldton Hospital

Heart Foundation

Indigenous Allied Health Australia

Indigenous Men's Referral and Assessment Service

James Cook University

Kambu Aboriginal and Torres Strait Islander Corporation for Health

Kimberley Aboriginal Medical Services Council

Kimberley Pilbara Medicare Local

Lung Foundation Australia

Majalla Inc.

Mater Health Services North Queensland

Menzies School of Health Research

Mercy Hospital for Women

Metro North Hospital and Health Service

Ministry for Health NSW

Mount Druitt Community Health Centre

Mura Kosker Sorority Inc.



National Aboriginal and Torres Strait Islander Health Worker Association	Tasmanian Government, The Department of Health and Human Services
National Aboriginal Community Controlled Health Organisation	The Alan Walker Cancer Centre The Lowitja Institute
National Breast Cancer Foundation	The Society of Hospital Pharmacists of Australia
National Health and Medical Research Council	Thursday Island Primary Health Care Centre
Northern Territory Medicare Local	Torres Strait and Northern Peninsula Area Health Community Council
Nyamba Buru Yawuru Ltd	University of South Australia
Peter MacCallum Cancer Centre	University of Sydney
Pink Diva's Breast Cancer Support Group, Ipswich & West Moreton	University of Melbourne
Port Kennedy Association Inc.	Victorian Aboriginal Community Controlled Health Organisation Inc.
Prostate Cancer Foundation of Australia	Victorian Aboriginal Community Services Association Limited
Queensland Aboriginal and Islander Health Council	Victorian Cervical Cytology Registry
Quit Victoria	Westmead Breast Cancer Institute
Royal Australian and New Zealand College of Radiologists	Westmead Hospital
South Australian Health and Medical Research Institute	West Moreton Hospital and Health Service
St. Vincent's Hospital Melbourne	Winnunga Nimmitjiah Aboriginal Health Service
Sydney Local Health District	Woomera Aboriginal Corporation
Tasmanian Aboriginal Centre Inc.	

# Glossary



**This glossary sets out how the following terms have been used in this Framework.**

Cancer continuum	A commonly used term in cancer control referring to the broad range of areas in which cancer-related services are provided, including prevention, early detection, diagnosis and treatment, survivorship and palliative care.
Cancer control	A term used to describe the broad range of activities carried out to address the impact of cancer by reducing cancer incidence and mortality and improving quality of life for people affected by cancer, through the systematic implementation of evidence based strategies for prevention, screening, early detection, diagnosis, treatment, supportive care, follow-up care, palliation and end of life care. <sup>11</sup>
Cancer related services	The broad range of services likely to be linked to cancer control in any way, including prevention, immunisation, screening, diagnosis, treatment, supportive care services, survivorship services, palliative care services, allied health services, accommodation, transport, health promotion, social security, etc.
Community based services	Services that are based in and provide services at the local community level; not necessarily health services. For example, community based services might include a resource service, youth service, counselling service or a cleaning service.
Community controlled primary health care service	A primary health care service with governance arrangements such as a community board, that allows the local Aboriginal and/or Torres Strait Islander community to be involved in its affairs in accordance with whatever protocols or procedures are determined by the community. <sup>30</sup>
Cultural competence	Cultural competence is used in this Framework to refer to organisational systems to describe quality care to clients with diverse values, beliefs and behaviours, including tailoring delivery to meet patients' social, cultural, and linguistic needs. It requires institutionalising of cultural knowledge, and adapting service delivery to reflect understanding of the diversity between and within cultures. <sup>31, 32</sup>
Culturally safe	'A culturally safe environment is one where we feel safe and secure in our identity, culture and community'. <sup>33</sup> An environment that is experienced as culturally unsafe will be seen as alienating, confronting, difficult and/or frightening; the individual may feel their culture is denied or invisible and that their views and wishes may not be respected. The Royal Australian College of General Practitioners refers to cultural safety as an environment that is 'safe for people: where there is no assault, challenge or denial of their identity, of who they are and what they need', where there is 'shared respect, shared meaning, shared knowledge and experience, of learning, living and working together with dignity and truly listening'. <sup>34</sup>
24 Enabler	A term used in this Framework to describe factors that may help in planning or reviewing strategies to address each of the priority areas for action.

Health professional	A term used in this Framework to refer to a person involved in providing health care, including doctors, nurses, Indigenous Health Workers, psychologists, oncologists, or counsellors.
Multidisciplinary care	Multidisciplinary care is an integrated team approach to health care in which medical and allied health care professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient. Multidisciplinary care involves all relevant health professionals discussing options and making joint decisions about treatment and supportive care plans, taking into account the personal preferences of the patient. <sup>35</sup>
Palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual. <sup>36</sup>
Primary health care services	Health care delivered through the General Practice sector, Aboriginal Community Controlled Health Organisation (ACCHO), community health services and/or state or territory primary health care services.
Quality improvement processes	Ongoing efforts to improve the quality of care, with an emphasis on improving processes and systems rather than individuals. Evidence shows that although health professionals believe they deliver good quality care, there is usually quite a gap between what is considered good quality care and what health professionals are able to deliver. Quality improvement processes use objective sources of information, for example, audits of patient records, to identify gaps where quality could be improved; to implement a change in routine practice to address the gap, and then review the data source to see if any improvement has occurred. A commonly-used approach to quality improvement is the Plan, Do, Study, Act (PDSA) cycle. An important aspect of quality improvement is that organisations use their own data to assess their own performance against identified indicators of quality care – assessment is not done externally.
Supportive care services	Supportive care is an umbrella term used to describe services which may be required by those affected by cancer. It includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care. All members of the multidisciplinary team have a role in the provision of supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

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The artwork 'Our Journeys' represents the experience of Aboriginal and Torres Strait Islander people with cancer. The white dots are the journey of each individual; the patterned areas are the different landscapes and regions of Australia; and the colours are the different cancer types. Cancer Australia, as the leading agency shaping cancer control in Australia, is depicted by the central ochre meeting place which draws stakeholders together to share ways to improve cancer outcomes. The kangaroo prints and the fish leading to and from the meeting place represent the flow of information and engagement between Cancer Australia and Aboriginal and Torres Strait Islander people.



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NFAT 08/15

