Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer

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Australian Government
Cancer Australia

Endorsed by
Cancer Council

Statement of acknowledgement

We acknowledge the Traditional Owners of Country throughout Australia and their continuing connection to the land, sea and community. We pay our respects to them and their cultures and to Elders past and present.

This work is available at cancer.org.au/ocp and canceraustralia.gov.au

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Foreword

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* has been developed with the aim of reducing disparities and improving outcomes and experiences for Aboriginal and Torres Strait Islander people with cancer.

Cancer is the third leading cause of burden of disease for Aboriginal and Torres Strait Islander people. While Australia's cancer survival rates are among the best in the world, Aboriginal and Torres Strait Islander people continue to experience a different pattern of cancer incidence and significant disparities in cancer outcomes compared with non-Indigenous Australians.

The pathway for patients undergoing diagnosis and treatment for cancer is complex, usually involving multiple healthcare providers across a range of settings, both public and private. While the clinical aspects of optimal care are the same for all people, irrespective of cultural heritage, optimal care should deliver health services that are culturally safe and responsive.

The distinct epidemiology of cancer among Aboriginal and Torres Strait Islander people, and unique connection to culture, highlight the need for an Optimal care pathway (OCP) for Aboriginal and Torres Strait Islander people with cancer. Ensuring this pathway is culturally safe and supportive is vital to addressing the disparities for Aboriginal and Torres Strait Islander people.
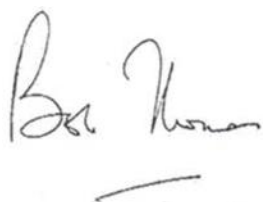
Tumour-specific OCPs have been developed with the aim of fostering an understanding of the whole pathway and its distinct components to promote consistent, quality cancer care and patient experiences. They act as a reminder that the patient is the constant in this journey, and that the health system has a responsibility to deliver the care experience in an appropriate, responsive and coordinated manner. The National Cancer Expert Reference Group (NCERG), established by the Council of Australian Governments (COAG) in 2010, has had oversight of the development of the OCPs, which are now being implemented across jurisdictions.

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* has been designed to complement the tumour-specific OCPs, focusing on the aspects of the care pathway that need to be responsive to the needs of Aboriginal and Torres Strait Islander people with cancer.

Its development has been guided by an Expert Working Group including Aboriginal and Torres Strait Islander leaders and health experts, and was underpinned by strong engagement and consultation with peak Aboriginal and Torres Strait Islander and health organisations, health professionals, consumers and carers. In addition Cancer Australia's Leadership Group on Aboriginal and Torres Strait Islander Cancer Control have provided significant strategic advice and input to the OCP development. We sincerely thank them all for their generous contributions.

Formal endorsement by NCERG and the Australian Health Ministers' Advisory Committee, acknowledges the importance of this OCP and the responsibility of the health system to deliver care in an appropriate, culturally safe, responsive and coordinated manner to ensure access and optimal health outcomes are experienced by all Australians.

Professor Robert Thomas
Special Advisor Health
Department of Health and Human Services
Co-chair NCERG

Dr Helen Zorbas
CEO
Cancer Australia

Summary

Please note that not all patients with cancer will follow every step of this pathway:

This Optimal care pathway provides guidance to health practitioners and service planners on optimal care for Aboriginal and Torres Strait Islander people with cancer, across the cancer continuum. Refer to the relevant tumour-specific Optimal Care Pathway at cancerorg.au/OCP.

For Aboriginal and Torres Strait Islander people, health and connection to land, culture, community and identity are intrinsically linked. Health encompasses a whole-of-life view and includes a cyclical concept of life-death-life.

Key considerations to support the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer:

Understanding your patient

- Understand the philosophies of holistic health and wellbeing and the role of Aboriginal and Torres Strait Islander knowledge, values, beliefs, cultural needs and health history in decision-making processes about treatment and ongoing care.

- Care coordination for each person should be informed by factors such as gender, kinship, family ties, language barriers and socio-economic issues.
  - Offer an option to see a health professional of the same gender as the patient, referral to an alternative service provider if this is not possible, or the option of having a support person present.
  - Acknowledge that family may include people who are not genetically related.

- When discussing family history and genetic testing, understand that the concept of family is broader than being genetically related, discussing family members who are part of the Stolen Generation may be distressing.

- Be sensitive when discussing cultural taboos about cancer, Sorry Business (referring to people that have died), Men's and Women's Business and concerns about research exposure.

- Practise trauma-informed care and take steps to address intergenerational and contemporary trauma through culturally informed approaches.

Communication

- Provide plain English information in accessible and culturally appropriate formats. Use an interpreter if required.

- Only use traditional terminology, such as referring to people as 'Aunty' or 'Uncle' if invited to do so.

Practical considerations for consultations

- Allow time to build rapport and trust with patients, while also ensuring timeframes meet evidence-based guidelines.

- Encourage and include family and/or community members/ Elders/support people at appointments, if preferred.

- Ask if the individual identifies as Aboriginal and/or Torres Strait Islander and record this if a person wishes to identify as such.

- Ask permission before touching a patient and explain the reasons why it is necessary to touch them.

- Ensure the multidisciplinary team includes an expert in providing culturally appropriate care to Aboriginal and Torres Strait Islander people.[1]

Step 1	Risk reduction:	Screening and immunisation:	Early detection:
Prevention and early detection	Encourage Aboriginal and Torres Strait Islander people to: • quit smoking • maintain a healthy body weight • be physically active • avoid or limit alcohol intake • eat a healthy diet • reduce ultraviolet exposure • consider risk-reducing surgery or medication for people with a high hereditary or genetic risk of certain cancers.	• encourage screening for colorectal, breast and cervical cancer • support uptake of immunisation for HPV and hepatitis B • encourage regular Medicare health assessments and use these opportunities to discuss prevention and early detection, and to assess cancer risk • discuss privacy concerns.	Timely diagnosis can be enabled by: • sharing knowledge about cancer, its symptoms and survivability • discussions addressing concerns or fears • increasing awareness of, and access to, affordable, convenient quality health services in remote and regional areas • considering comorbidities masking cancer symptoms.

1 A culturally appropriate healthcare professional may be an Aboriginal and Torres Strait Islander Health Worker, Health Practitioner, or Hospital Liaison Officer.

Step 2

Presentation, initial investigations and referral

Presentation: Some Aboriginal and Torres Strait Islander people may:

- present with multiple comorbidities
- have multiple risk factors
- present with a later stage of disease
- avoid discussing gender-specific matters in the presence of a member of the opposite gender
- feel culturally unsafe accessing health services
- face financial, transport or other barriers to accessing health services
- have family and community responsibilities
- experience feelings of shame or discomfort from heightened attention, sharing personal information, previous experiences or perceptions about cancer or mainstream medical services.

Referral: If test results are equivocal, or if the diagnosis of cancer is confirmed, referral to an appropriate specialist is warranted. Timely follow up regarding status of referral is essential.

- Ensure contact details are up to date to enable follow-up, and Aboriginal and/or Torres Strait Islander status is recorded (with consent).
- Designate a culturally appropriate healthcare professional[2] to follow up on the referral and keep in contact with the patient.

Timeframes: Communication technologies and additional discussions may facilitate the involvement of family members and carers in decision making within optimal care timelines.

Support and communication – lead clinician to:[3]

- ask whether the patient wishes a support person to be present during discussions
- routinely identify the supportive care needs of the patient and their families, ideally through using a tool validated for use with Aboriginal and Torres Strait Islander people, for example SCNAT-IP[4]
- provide the patient with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for appointments
- provide information about local support services
- support the patient while waiting for the specialist appointment. Local health professionals and/or Cancer Council nurses can provide information and reassurance via the national 13 11 20 information and support service. Health Professionals can also access this service.

Step 3

Diagnosis, staging and treatment planning

Care coordination is critical to facilitate and optimise the timeline between diagnosis, staging and treatment planning.

Diagnosis and staging: The diagnostic workup depends on the type of cancer involved. Some procedures may require the patient to travel to receive care at a specialised centre, which could be arranged through jurisdictional Patient Assistance Travel Schemes and with assistance by an Aboriginal and/or Torres Strait Islander Hospital Liaison Officer. All patients should be assessed for medical comorbidities during the diagnostic workup.

Treatment planning: Newly diagnosed patients should be discussed by a multidisciplinary team that includes an expert in providing culturally appropriate care to Aboriginal and Torres Strait Islander people[5], to recommend a treatment plan.

Research and clinical trials: Consider enrolment in relevant clinical trials for patients as part of treatment planning. To achieve equity of access for Aboriginal and Torres Strait Islander people, clinicians should use culturally appropriate resources to explain the benefits of the clinical trials.

Support and communication – lead clinician to:

- discuss the reason investigations are being conducted to help the patient understand their situation and discuss concerns before providing informed consent for the diagnostic workup
- establish if the patient has a regular or preferred general or primary practitioner
- discuss a timeframe for diagnosis and treatment with the patient/carer support person
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- invite the general practitioner to multidisciplinary team meetings (consider video or teleconferencing)
- notify the general or primary practitioner, Aboriginal and/or Torres Strait Islander Health Worker or Hospital Liaison Officer and family or carer if the person does not attend clinic appointments
- provide appropriate information or refer to support services as required. Cancer Council nurses can provide information and reassurance via the national 13 11 20 telephone support service.

2 This may be an Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Hospital Liaison Officer, or a Primary Healthcare Coordinator.

3 Lead clinician – the clinician who is responsible for managing patient care. The lead clinician may change over time.

4 The Supportive Care Needs Assessment Tool for Indigenous People, available at at <http://www.scnatip.org/>.

5 A culturally appropriate healthcare professional may be an Aboriginal and Torres Strait Islander Health Worker, Health Practitioner, or Hospital Liaison Officer.

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 4
Treatment

Treatment intent: Establish and document if treatment is

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure or
- symptom palliation.

When discussing death or dying with Aboriginal and Torres Strait Islander people, the terms 'passing', 'not going to get better' or 'returning to Country' may be more accepted due to spiritual belief around the life cycle (seek guidance from Aboriginal and/or Torres Strait Islander Health Worker or Hospital Liaison Officer).

Treatment options: Aboriginal and Torres Strait Islander perception and view of health, illness and treatment may impact on decision making. When discussing treatment options with the patient and carer/support person, lead clinician to consider:

- preferred place of treatment
- travel and accommodation needs
- cultural obligations, including family and community
- engagement with identified health professionals (for example an Aboriginal and/or Torres Strait Islander Health Worker)
- involvement of spiritual advisors, traditional healers and traditional medicine.

Pain management: Aboriginal and Torres Strait Islander patients may not actively report pain or other needs. The lead clinician should be proactive about determining the appropriate time for referral to palliative care for symptom control. Consider:

- offering the option for patients to discuss pain management with a health professional of the same gender
- offering oral pain relief options where appropriate
- using a pain tool that is culturally appropriate for the local community
- fully explaining options, usage and side effects of pain relief.

Palliative care: Early referral can improve quality of life and, in some cases, survival. Referral should be based on need, not prognosis.

> **Support and communication – lead clinician to:**
> - discuss treatment options with the patient/carer/support person including the intent of treatment and expected outcomes
> - discuss advance care planning with the patient/carer/support person where appropriate
> - discuss the treatment plan with the patient's general practitioner
> - discuss and document the patient's use (or intended use) of traditional or complementary or alternative medicine therapies.

Step 5
Care after initial treatment and recovery

Consider if additional support is needed to support a healthy lifestyle.

Strategies to assist with the transition to survivorship after treatment ends include:

- engaging Aboriginal and/or Torres Strait Islander Health Workers, Health Practitioners, the Primary Healthcare Coordinator and/or Hospital Liaison Officer to support the person
- discussing the patient's beliefs and definition of living well to ensure health services are working towards the patient's ideal outcome

- offering referral pathways to social and emotional wellbeing services and mental health services.

Treatment summary (provide a copy to the patient/carer and general practitioner) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided

- contact information for key care providers.

Follow-up care plan (provide a copy to the patient/carer and general practitioner) outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- potential barriers to the follow-up plan (travel or cost) and strategies or referrals to support services to address these
- a process for rapid re-entry to medical services for suspected recurrence.

> **Support and communication – lead clinician to:**
> - explain the treatment summary and follow-up care plan to the patient/carer
> - provide culturally appropriate information about the signs and symptoms of recurrent disease, secondary prevention and healthy living
> - discuss the follow-up care plan with the general practitioner
> - consider that the term 'survivor' may have negative connotations for historical reasons.

Step 6
Managing recurrent, residual and metastatic disease

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the type, location and extent of disease, previous management and patient preferences.

Pain management: Aboriginal and Torres Strait Islander patients may not actively report pain or other needs, therefore the lead clinician should be proactive about determining the appropriate time for referral to palliative care for symptom control.

Consider:

- offering the option for patients to discuss pain management with a health professional of the same gender
- offering oral pain relief options where appropriate
- using a pain tool that is appropriate for the local community
- fully explaining options, usage and side effects of pain relief.

Palliative care: Early referral can improve quality of life and, in some cases, survival. Referral should be based on need, not prognosis.

Support and communication – lead clinician to:
- explain the treatment intent, possible outcomes, adverse effects and the supportive care options available
- consider that when discussing death or dying with Aboriginal and Torres Strait Islander people, the terms 'passing' or 'not going to get better' or 'returning to Country' may be more accepted due to spiritual belief around the life cycle (seek guidance from Aboriginal and/or Torres Strait Islander Health Worker or Hospital Liaison Officer)
- initiate a discussion regarding advance care planning if appropriate.

Step 7
End-of-life care

Wherever possible and requested by the patient and/or their family or carers, health services should support the inclusion of cultural practices, which may include the services of a spiritual advisor, traditional healer or Elders, access to traditional foods, and performing ceremonies.

Return to Country: The need to 'return to Country' before the end or at the end of life can be both culturally and spiritually significant. Where the patient prefers to be cared for at home, health services should act to support the family and carers in providing appropriate palliative care.

Multidisciplinary palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Pain management: When assessing pain and pain management, health professionals should be aware that there are significant cultural practices regarding which family members can assist with providing pain relief, how pain medication is administered, and fears that pain relief medicines may accelerate the passing of the patient.

Effective strategies to manage pain for Aboriginal and Torres Strait Islander people include:

- offering the option for patients to discuss their pain and pain management with a health professional of the same gender
- offering oral pain relief options where appropriate
- using a pain tool that is culturally appropriate for the local community
- fully explaining options, usage and side effects of pain relief.

Practices around death and dying: The practices observed around death and dying can vary significantly between both individuals and Aboriginal and Torres Strait Islander communities. Health services should discuss cultural preferences with all patients and consult with their local Aboriginal and Torres Strait Islander personnel and communities for further guidance about this. It may be inappropriate to say or write the name of a deceased person, or for a non-Indigenous health professional to relay the news that an Aboriginal and/or Torres Strait Islander person has died.

Support and communication – lead clinician to:
- be open to and encourage discussion about the expected disease course while considering the patient's personal and cultural beliefs and expectations
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

Context

This section of the Optimal care pathway (OCP) provides context about the impact and burden of cancer on Aboriginal and Torres Strait Islander people to explain why this OCP is important.

The distinct epidemiology of cancer among Aboriginal and Torres Strait Islander people and its unique connection to culture highlight the need for an Optimal care pathway for Aboriginal and Torres Strait Islander people.

In 2015 Cancer Australia developed an evidence-based, nationally agreed strategic framework to guide future cancer control efforts for Aboriginal and Torres Strait Islander people. The first *National Aboriginal and Torres Strait Islander Cancer Framework* identifies seven priorities to guide and inform national, jurisdictional, regional and local cancer control efforts. Priority Five is to 'ensure Aboriginal and Torres Strait Islander people affected by cancer receive optimal and culturally appropriate treatment, services, and supportive and palliative care' (Cancer Australia 2015 p. 15).

Cancer Australia has partnered with the Victorian Department of Health and Human Services to develop the *OCP for Aboriginal and Torres Strait Islander people with cancer* as part of the National Cancer Expert Reference Group's program of work.

This pathway provides guidance about providing culturally safe and responsive healthcare for Aboriginal and Torres Strait Islander people.

Educating health professionals about unconscious bias and how a person's culture, values and motivations influence their practice is essential for creating a culturally competent workforce.

The clinical aspects of optimal care are the same for all people, irrespective of cultural heritage; however, optimal care, by definition, should deliver health services in a way that is culturally responsive and safe.

While Australia's cancer survival rates are among the best in the world, Aboriginal and Torres Strait Islander people continue to experience disparities in cancer outcomes.

Cancer is the third leading cause of fatal burden of disease for Aboriginal and Torres Strait Islander people (Australian Institute of Health and Welfare 2016a) who are, on average, 40 per cent more likely to die from cancer than non-Indigenous Australians (Australian Institute of Health and Welfare 2018). Cancer places a heavy burden not only on those diagnosed with the disease but also their families, carers, Elders and community.

Aboriginal and Torres Strait Islander people have a different pattern of cancer incidence, with some cancers occurring more commonly than among non-Indigenous Australians (Cancer Australia 2015; Australian Institute of Health and Welfare 2014). There is a higher incidence of cancers that are preventable (for example, gynaecological and head and neck cancer) and are more likely to be fatal (for example lung, cervical and liver cancer) (Australian Institute of Health and Welfare 2017a).

Aboriginal and Torres Strait Islander people continue to face significantly higher risk factors for cancer. For instance, the smoking rate for Aboriginal and Torres Strait Islander people aged 15 or older is about 40 per cent compared with about 14 per cent in non-Indigenous Australians (Australian Bureau of Statistics 2016a). Aboriginal and Torres Strait Islander people also have higher levels of other modifiable risk factors for cancer including obesity, lack of physical activity, risky levels of alcohol consumption and hepatitis B and C infection (Cancer Australia 2015, Condon 2004, Cunningham et al 2008, National Notifiable Diseases Surveillance System Annual Report Working Group 2016, The Kirby Institute 2016).

Cancer screening program participation rates are generally lower among Aboriginal and Torres Strait Islander people (Australian Institute of Health and Welfare & Cancer Australia 2013), and Aboriginal and Torres Strait Islander people are more likely than other Australians to be diagnosed when cancer is at an advanced stage of disease (Diaz et al. 2015) and are less likely to be hospitalised for cancer care (Australian Institute of Health and Welfare 2015). Aboriginal and Torres Strait Islander people may have poor access to healthcare services due to financial, language, cultural or geographical barriers (Australian Institute of Health and Welfare & Cancer Australia 2013).

These disparities in cancer outcomes and overall poorer survival are significantly influenced by the social determinants of health – social factors such as education, employment, contact with the justice system, income and housing that affect a person's health and wellbeing at each stage of life (Department of Health 2017b; The Lowitja Institute 2014). There is also strong evidence emerging about the ways that cultural factors link to health and wellbeing and can support better health outcomes (Department of Health 2017b). Protecting and promoting the cultural determinants of health, including connections to culture and Country, lead to improved outcomes across the other determinants of health (The Lowitja Institute 2014).

For Aboriginal and Torres Strait Islander people, racism, marginalisation and societal lack of understanding of Aboriginal and Torres Strait Islander culture, disruption of Aboriginal and Torres Strait Islander people's ties to land, and living in remote areas can negatively influence the social determinants and cultural determinants of health (Aboriginal and Torres Strait Islander Social Justice Commissioner 2005; Osborne et al. 2013).

There are numerous inequities between Aboriginal and Torres Strait Islander people and non-Indigenous people in Australia resulting from European contact and historical government policies. These inequities continue to affect Aboriginal and Torres Strait Islander people and are reflected through socioeconomic factors such as lower incomes, poorer education, higher rates of unemployment, higher levels of isolation and shorter life expectancy, compared with non-Indigenous Australians (Australian Institute of Health and Welfare 2016).

The 2014–15 National Aboriginal and Torres Strait Islander Social Survey reports on 7,022 Aboriginal and Torres Strait Islander people aged 15 years and over. One-third (33 per cent) of respondents felt they had been treated unfairly at least once in the previous 12 months because they were of Aboriginal or Torres Strait Islander origin. Although these statistics are not health-specific, these experiences can affect access to health services, with around one in seven Aboriginal or Torres Strait Islander people (14 per cent) having avoided situations in the 12 months preceding the survey due to being treated unfairly in the past (Australian Bureau of Statistics 2016b). Unconscious or implicit bias from health workers is particularly detrimental and may perpetuate the inequities and poorer health outcomes experienced by Aboriginal and Torres Strait Islander people.

In addition, approximately 35 per cent of Aboriginal and Torres Strait Islander people live in major cities, 44 per cent in inner or outer regional areas, and 21 per cent in remote or very remote areas, making them disproportionately disadvantaged by rurality (Australian Bureau of Statistics 2011). It is well established that cancer patients living in regional or remote parts of Australia experience poorer cancer outcomes compared with patients in metropolitan areas, and this gap widens with the increasing remoteness of the location (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries 2003; Coory et al. 2013; Jong et al. 2004).

The existing evidence of variation in cancer outcomes for Aboriginal and Torres Strait Islander people in remote compared with metropolitan areas is limited but does suggest Aboriginal and Torres Strait Islander patients are less likely to survive their cancer the further they live from urban centres (Diaz et al. 2015).

It is likely that access to healthcare, the environment and other risk factors contribute to the disparity in outcomes for residents of regional or remote areas.

Intent and key principles

This section sets out the purpose of the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* and the principles and concepts that underpin its development.

The OCPs that map the entire cancer pathway for specific tumour types aim to provide a template for evaluating cancer care programs, as well as foster an understanding of the whole cancer pathway and its distinct components to promote quality cancer care and patient experiences.

The purpose of this OCP for Aboriginal and Torres Strait Islander people with cancer is to complement the best practice information provided in the tumour-specific pathways to facilitate the delivery of culturally safe and competent care. For health services to be effective in Aboriginal and Torres Strait Islander health they must operate in ways that show both understanding of and respect for Aboriginal and Torres Strait Islander culture. This document therefore focuses on the aspects of the cancer care pathway that need to be responsive to the needs of Aboriginal and Torres Strait Islander people with cancer.

Health services and health professionals can use this OCP as a tool to identify gaps in current cancer services and to inform quality improvement initiatives across all aspects of the care pathway. Clinicians can also use the OCP as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer. The evidence-based principles set out in the tumour-specific pathways have been considered in developing this guidance. These are:

• patient-centred care
• safe and quality care
• multidisciplinary care
• supportive care
• care coordination
• communication
• research and clinical trials.

Each of these principles is detailed in this section. They are underpinned by the evidence-based principles and key concepts set out in Cancer Australia's *National Aboriginal and Torres Strait Islander Cancer Framework* (2015):

• Aboriginal and Torres Strait Islander people are engaged and involved throughout the planning, design and delivery of cancer services.
• Patients, families, carers and communities are informed and empowered.
• We are working together towards a common goal.
• Policy and practice is informed by reliable data and evidence about what works.

Key concepts that are fundamental to Aboriginal and Torres Strait Islander health include:

• providing a holistic approach to health and wellbeing
• acknowledging the diversity of Aboriginal and Torres Strait Islander peoples
• understanding the social determinants and cultural determinants of health (Cancer Australia 2015).

Patient-centred care

Patient- or consumer-centred care is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. For Aboriginal and Torres Strait Islander people, optimal patient-centred care includes acknowledging the philosophies of holistic health and wellbeing, and the role of Aboriginal and Torres Strait Islander knowledge, values, beliefs, cultural needs and health history in decision making about treatment and ongoing care. Patient-centred care also considers the impact of family structures and responsibilities including kinship (Council of Australian Governments 2016). It is also important to recognise that for Aboriginal and Torres Strait Islander people health means not just the physical wellbeing of an individual but refers 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, thereby bringing about the total wellbeing of their community. It is a whole-of-life view and includes the cyclical concept of life–death–life (National Aboriginal Community Controlled Health Organisation 2017).

In practising patient-centred care, the impacts of trauma across generations of Aboriginal and Torres Strait Islander people must be acknowledged and addressed. Health services and programs should practise trauma-informed care, understanding that trauma can influence the way people approach the health system and that the biological impact of stress and trauma can be an underlying cause of poor health. The trauma of historical events, including those associated with colonisation, can pass to children (intergenerational trauma), and some people directly experience trauma through exposure to an accident, family violence and abuse (Atkinson 2013). Steps should be taken to address intergenerational and contemporary trauma through culturally-informed approaches. These approaches must recognise the unique history across communities and cultures and that the impact of trauma will be different depending on this history (Department of Health 2017a).

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 (Hunt 2013; Osborne et al. 2013).

Safe and quality care

Safe and quality care is provided by appropriately trained and credentialled clinicians, hospitals and clinics that have the equipment, staffing capacity and service evaluation programs to support safe and high-quality care.

All health services should prioritise creating a culturally competent workforce. This means ensuring that all health professionals, health managers, receptionists and administrative workers working with Aboriginal and Torres Strait Islander patients have adequate ongoing training and skills in delivering culturally safe healthcare and medical advice (Cancer Australia 2015).

Studies have shown disparities in medical care experienced by Aboriginal and Torres Strait Islander patients in Australia. Aboriginal and Torres Strait Islander patients with the same characteristics as non-Indigenous patients were about a third less likely to receive appropriate medical care across all conditions (Cunningham 2002) including lung cancer (Hall et al. 2004).

Unconscious or implicit biases occur when individuals make automatic negative judgements about people based on irrelevant characteristics such as race or gender, influenced by their own background, culture and personal experiences. Unconscious or implicit bias from health workers is particularly detrimental and may perpetuate the inequities and poorer health outcomes experienced by Aboriginal and Torres Strait Islander people (Cunningham 2002).
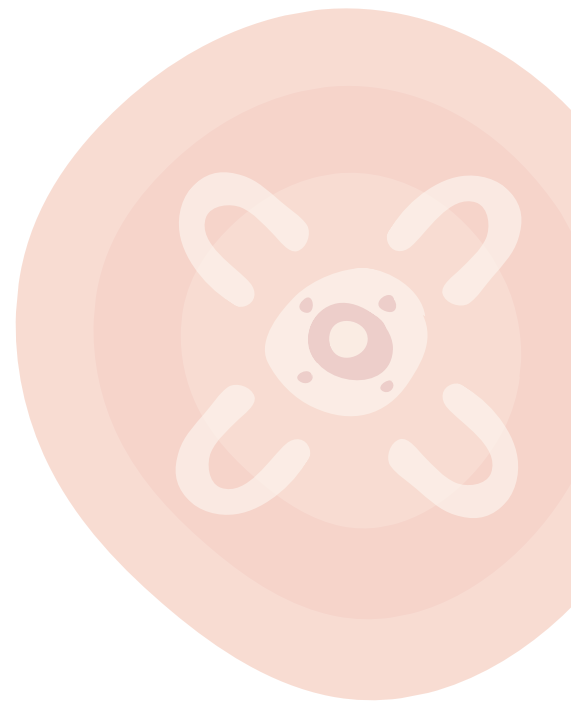
Racism and unconscious bias can be experienced at the individual level as well as the institutional level through built-in operations and systems; there is an opportunity to improve health outcomes for Aboriginal and Torres Strait Islander people by addressing this at both the individual and system levels (Council of Australian Governments 2016).

It is important to educate health professionals about institutional racism and unconscious bias because it may embed discrimination into the operations of health systems (Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee 2016).

Building a culturally competent workforce also includes the availability and early engagement of:

- care coordinators and navigators
- Aboriginal and/or Torres Strait Islander Health Workers
- Aboriginal and/or Torres Strait Islander Health Practitioners
- Aboriginal and/or Torres Strait Islander Hospital Liaison Officers, preferably trained in cancer care
- medically trained interpreters
- both male and female health professionals (for 'Men's Business' and 'Women's Business').

All patients should be asked whether they identify as Aboriginal and/or Torres Strait Islander, and this should be clearly documented. Patients may not wish to identify themselves an Aboriginal and/or Torres Strait Islander, which must be respected. Health services are encouraged to work in partnership with Aboriginal and Torres Strait Islander people to determine how data can be used to evaluate the experience of care, programs and service models. This will require improving the identification of Aboriginal and Torres Strait Islander patients (Cancer Australia 2015).

Further information

- Refer to the Cultural Respect Framework 2016 – 2026 for Aboriginal and Torres Strait Islander Health: <http://www.coaghealthcouncil.gov.au/Portals/0/National%20Cultural%20Respect%20 Framework%20for%20Aboriginal%20and%20Torres%20Strait%20Islander%20Health%20 2016_2026_2.pdf>.
- Refer to the Australian Commission on Safety and Quality in Health Care 2016: <https://www. safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/improving-care-for-aboriginal-and-torres-strait-islander-people/>.
- View the national standards for collecting Indigenous status data at <https://www.aihw.gov.au/ reports/indigenous-australians/national-guidelines-collecting-health-data-sets/contents/table-of-contents>.
- Access the Consumer's Perspective of the Quality of Care Survey Protocol 2015 at <http://www. menzies.edu.au/icms_docs/253219_2016_Release_Consumers_Perspective_Protocol.pdf>.

Multidisciplinary care

Multidisciplinary care is considered the cornerstone of best practice cancer care, and all patients should have the benefit of multidisciplinary treatment planning. This is an integrated team approach to healthcare in which medical and allied health professionals including Aboriginal and Torres Strait Islander health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient. Specific multidisciplinary team members will depend on the cancer type and are outlined in the tumour-specific OCPs.

For Aboriginal and Torres Strait Islander patients, it is essential that the team includes an expert in providing culturally appropriate care to this population.

The multidisciplinary team should consider the patient's kinship and family ties, as well as their personal, social and cultural circumstances, and factor these into the person's treatment plan.

Supportive care

Supportive care is an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes.

Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.

For Aboriginal and Torres Strait Islander people affected by cancer, there may be specific supportive care needs, including across the following domains:

- hospital care
- information and communication
- physical and psychological needs
- practical and cultural needs (Garvey et al. 2012; Garvey et al. 2015).

Needs assessments are commonly used as a screening tool to identify, from the patient's perspective, unmet supportive care needs and to assess the priority and extent of support that is required. The needs of Aboriginal and Torres Strait Islander people with cancer should be assessed using a culturally-specific screening tool. Needs assessments should be conducted routinely and systematically across the cancer continuum, as issues patients face and the support they need to resolve these needs can change over time (Valery et al. 2016). The needs of family and other caregivers should also be assessed, so that those supporting Aboriginal and Torres Strait Islander cancer patients through their cancer journey are also supported.

All members of the multidisciplinary team have a role in providing supportive care. In addition, support from Aboriginal Community Controlled Health Service, Aboriginal Medical Services, family, friends, Elders, community, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

Further information

- The Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) is a useful tool for identifying the needs of adult Aboriginal and Torres Strait Islander cancer patients. Learn about the SCNAT-IP tool at <http://www.scnatip.org/>.
- The National Comprehensive Cancer Network (NCCN) distress thermometer is a screening tool validated in the general population. Learn more about the distress thermometer at <http://edcan. org.au/edcan-learning-resources/supporting-resources/supportive-care/screening>.

Care coordination

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach seeks to ensure care is delivered in a logical, connected and timely manner so the medical and personal needs of the patient are met. Effective care coordination for Aboriginal and Torres Strait Islander people requires building relationships and trust, and ensuring the workforce is culturally competent (through additional training, skills and knowledge attainment). Gender, kinship and family ties, language barriers and socioeconomic issues should be addressed to provide individualised care coordination for all patients.

In the context of cancer, care coordination encompasses multiple aspects of care delivery including multidisciplinary team meetings, patient travel logistics, supportive care screening/assessment, family and carer support, navigation and referral systems, comorbidities management, data collection, development of common protocols, information provision, informed consent with decision support and individual clinical treatment.

Improving care coordination is the responsibility of all health professionals involved in the care of patients. Enhancing continuity of care across the health sector requires a whole-of-system response. In practice, care coordination for individuals is often led by an assigned team member or care coordinator.

Within the primary healthcare sector, care coordination often involves broader coordination activities including advocating on behalf of the patient, ensuring culturally safe and responsive services are received, supporting the patient to attend appointments, monitoring and encouraging completion of treatment, streamlining referral systems to specialists, providing health education as appropriate and identifying when further assistance from a health professional is required.

Due to the high prevalence of comorbidities among Aboriginal and Torres Strait Islander populations (Australian Indigenous Health*Info*Net 2017), some Aboriginal and Torres Strait Islander people may have an established or ongoing relationship with a primary health care coordinator (under Integrated Team Care arrangements) who may provide valuable coordination assistance throughout a patient's cancer journey.

Regular and timely two-way communication between the lead clinician and the person's general or primary practitioner or primary care provider is an essential component of optimal care coordination and may involve:

- gathering information from the local Aboriginal Community Controlled Health Service, Aboriginal Medical Service or general or primary practitioner including their perspective on the person (psychological issues, cultural preferences, social issues and comorbidities) and locally available support services
- notifying the general or primary practitioner, Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner and/or Hospital Liaison Officer and family/carer if the person does not attend clinic appointments
- discussing shared care arrangements, including contributing to a chronic disease and mental healthcare plan as required
- establishing the role of the general or primary practitioner in symptom management, psychosocial care and referral to local services.

Regional and remote health services can improve access to care by:

- developing strategies to attract and retain experienced health professionals
- enhancing care coordination
- using telehealth to improve access to further specialist services
- improving partnerships between clinician groups, teams and individual healthcare practitioners in smaller health services with regional or metropolitan health services
- providing health professionals with access to continued professional development opportunities
- facilitating easier access to relevant support services such as by providing assistance with financial and transport issues.

When a primary health care coordinator is not available or nominated to support an Aboriginal or Torres Strait Islander person throughout the cancer continuum, an Aboriginal and/or Torres Strait Islander Health Worker or other identified Aboriginal and/or Torres Strait Islander health professional may be assigned the tasks of a care coordinator.

Informing all care coordinators in all services at key steps of the cancer pathway or when individual health plans change will help provide seamless transitions and continuity of care to the patient.

Further information

- View the Interpretive guide to the RACGP Standards for general practices (4th edition) for Aboriginal community controlled health services at <www.racgp.org.au/your-practice/standards/interpretiveguide4thedition/>.
- The National Aboriginal Community Controlled Health Service is the national peak body representing more than 150 Aboriginal community-controlled health services across the country on Aboriginal health and wellbeing issues. Visit <http://www.naccho.org.au/>.

Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, their families, supporters and carers are met. Effective communication is essential at every step of the care pathway and may be affected by language barriers or cultural differences when a patient, family member, support person or carer identifies as an Aboriginal and/or Torres Strait Islander person (Ha & Longnecker 2010).

Communication with patients should be:

- respectful
- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive and appropriate – that takes account of gender (Men's and Women's Business), family ties, language barriers, health literacy and socioeconomic issues
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families (with their consent).

Using appropriate technology such as telehealth and other resources/tools can help facilitate effective communication.

Healthcare providers could also consider offering the patient a Question Prompt List (QPL) in advance of their consultation, as well as recordings or written summaries of their consultations. QPL interventions are effective in improving the communication, psychological and cognitive outcomes of cancer patients (Brandes et al. 2015). Providing recordings or summaries of key consultations may improve the patient's recall of information and patient satisfaction (Pitkethly et al. 2008).

Research and clinical trials

Where practical, patients should be offered the opportunity to participate in research or clinical trials at any stage of the care pathway while being reassured that opting not to participate in research will not affect the standard of care they receive. A requirement of clinical trials conducted in Australia is adherence to a set of national standards that protect the cultural needs of Aboriginal and Torres Strait Islander people (National Health and Medical Research Council 2003; National Health and Medical Research Council et al. 2007). Research and clinical trials play an important role in establishing efficacy and safety for a range of treatment interventions, as well as establishing the role of psychological, supportive and palliative care interventions (Sjoquist & Zalcberg 2013).

While individual patients may or may not receive a clinical benefit from the intervention, there is evidence that the outcomes for anyone who participates in research and clinical trials are generally improved, perhaps due to the rigour of the process required by the trial. Leading cancer agencies often recommend participating in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participating in research and clinical trials will contribute to the care of cancer patients in the future (Peppercorn et al. 2004).

To achieve equity in the participation rate of Aboriginal and Torres Strait Islander people in clinical trials, clinicians should use culturally appropriate resources to better inform patients about the benefits of the trials.

Further information

- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <http://www.australiancancertrials.gov.au/>.
- See the National Health and Medical Research Council's Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research at <https://www.nhmrc.gov.au/guidelines-publications/e52> and Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics at <https://www.nhmrc.gov.au/guidelines-publications/e65>.

Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer

This section provides information and guidance regarding how to support key principles and concepts to help deliver optimal care for Aboriginal and Torres Strait Islander people with cancer, under the following themes:

- healthcare environment
- relationship building with the local community
- cross-cultural communication
- Men's and Women's Business
- health literacy
- culturally appropriate resources.

This information is likely to be relevant across all steps in the OCP, and further detail is provided below.

Healthcare environment

Optimal cancer care begins with creating a safe, welcoming and inclusive environment for all patients, acknowledging that hospitals may be considered a place of fear for some Aboriginal and Torres Strait Islander people. Creating an optimal care environment for Aboriginal and Torres Strait Islander people can be facilitated by:

- engaging with local Aboriginal and Torres Strait Islander people, communities and organisations to establish and maintain good working relationships, including seeking feedback on cultural inclusiveness and if any improvements can be made to the health service environment(s) across the entire health workforce and care continuum

- partnering with Aboriginal Community Controlled Health Services and Aboriginal Medical Services as appropriate to deliver and coordinate prevention, screening and care activities

- creating a safe, welcoming and inclusive environment through displaying an acknowledgement of the Traditional Custodians of the land and promoting Aboriginal and Torres Strait Islander culture via artwork, signage and music in patient areas

- accommodating and encouraging the inclusion of multiple family and/or community members/ Elders at appointments, including the use of modern technology to facilitate this (this may require additional support (such as accommodation) for rural/regional patients, family and/or community members/Elders where treatment is delivered in metropolitan health services)

- employing Aboriginal and Torres Strait Islander people in health services across all levels of care delivery and the cancer continuum

- providing outdoor spaces or gardens for patient and family areas, where possible.

Concerns about privacy, particularly in regional or remote areas with smaller populations, may arise. These can be addressed by:

- reassuring people during health information sessions and in printed resources that health professionals have to abide by a privacy code of conduct
- allowing flexibility with appointments to enable patients to meet with preferred health professionals
- providing referrals to other health services, should a patient not be comfortable being seen at their local health service.

Teleoncology may also be an acceptable model of care for Aboriginal and Torres Strait Islander patients (Mooi et al. 2012). Health professionals who provide teleoncology services need to adapt to the needs of individual patients and local communities to provide culturally appropriate care. Formal skills training for staff, informed consent procedures and effective communication between specialists and local health professionals are essential to maintaining the safety of practices (Mooi et al. 2012).

Relationship building with the local community

Engaging and involving local Aboriginal and Torres Strait Islander communities early in both the planning and the delivery of health services and programs is an important way to develop a strong relationship with the local community. This may be achieved by improving familiarity with local Aboriginal or Torres Strait Islander history, organisations (such as Aboriginal community-controlled health services or the Aboriginal Land Council), Elders and other members of the community. Building strong relationships with Aboriginal and Torres Strait Islander communities will help foster referral pathways to culturally responsive and safe services.

Relationships with local Aboriginal and Torres Strait Islander communities can be strengthened through:

- informal meetings and discussions between non-Indigenous service providers, their Aboriginal and Torres Strait Islander counterparts and Aboriginal and Torres Strait Islander people
- running open days and community events at hospitals
- attending local Aboriginal community events
- considering best practice cancer care for Aboriginal and Torres Strait Islander people when developing and implementing practice and service guidelines.

When establishing relationships and consulting with your local Aboriginal and Torres Strait Islander communities, it is recommended to:

- contact local Aboriginal and Torres Strait Islander agencies to help identify the correct person or group to talk to and the preferred way to approach that person or group
- check whether relevant consultation processes have been recently undertaken to avoid repetitive requests and excessive demands on the communities.

Cross-cultural communication

A fundamental step towards improving health outcomes for Aboriginal and Torres Strait Islander people is to incorporate culturally respectful communication into the mainstream health system, which does not necessarily align with, and is not responsive to, Aboriginal and Torres Strait Islander people and cultures (Council of Australian Governments 2016).

Cross-cultural communication skills may require specific training and can be assisted by:

- making time during explanations and appointments to build rapport and trust with patients and not rushing patients
- considering that English may not be the patient's first language
- avoiding compound questions and instead asking single questions at a time
- using culturally appropriate visual aids such as diagrams, images and DVDs
- appreciating potential differences in the use of non-verbal communication such as silence or, in some cases, a lack of direct eye contact
- respecting privacy by avoiding discussions in public areas and appreciating the concept of Men's and Women's Business (addressed in further detail in the *Men's and Women's Business* section)
- being mindful of questions that can seem intrusive (for example, minimise confrontation by beginning with 'Maybe this is a bit embarrassing to ask you about, but …')
- encouraging patients to express their concerns, needs and emotional states, recognising that patients may feel discomfort and in some circumstances shame over sharing personal and private issues, or in situations where they do not understand the medical information being discussed
- using the services of an Aboriginal and/or Torres Strait Islander Hospital Liaison Officer, where appropriate
- ensuring shared decision making whereby clinicians and patients make decisions about the patient's treatment together, if this is the patient's preference.

Throughout the cancer care pathway, the general practitioner or lead clinician should:

- ask the patient if they'd like an Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Hospital Liaison Officer, or other health professional present during consultations and discussions
- ask whether the person wishes for a family member or other support person to be present during discussions
- offer individualised tumour-specific information that meets the needs of the patient and their carer(s)
- offer advice on how to access information and support from websites, community and national cancer services and support groups for both patients and carers, including Aboriginal and Torres Strait Islander support groups, which may offer a safe alternative to those offered within mainstream services
- provide the patient with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for appointments
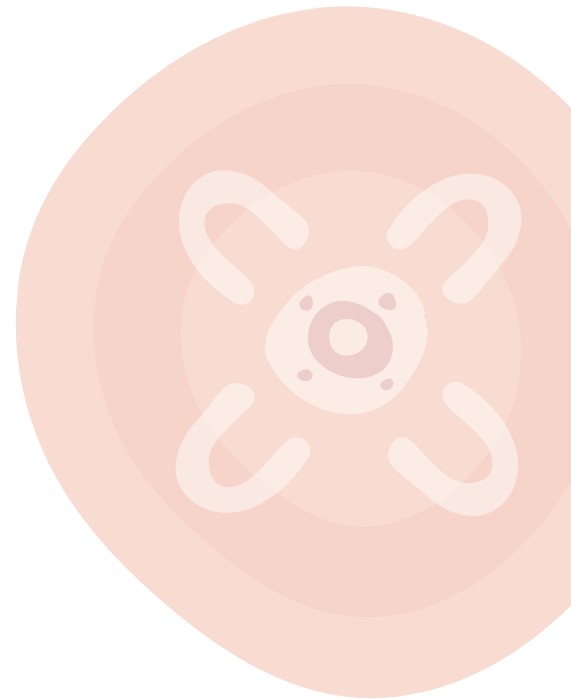- support the patient while waiting for the specialist appointment.

Recognising that hearing impairment disproportionally affects Aboriginal and Torres Strait Islander children and adults, consider its contribution to potential disengagement or ineffective communication (Australian Bureau of Statistics 2013). Because hearing loss affects many social determinants such as literacy, communication strategies may require further individualisation.

Health professionals should be sensitive about using traditional terminology such as referring to people as 'Aunty' or 'Uncle' without being invited to do so. It is essential that effective communication is achieved before patients can provide informed consent for medical procedures. If there are any concerns about comprehension or establishing a two-way dialogue with Aboriginal and Torres Strait Islander patients, the services of a medically trained interpreter and/or an Aboriginal and/or Torres Strait Islander, Hospital Liaison Officer or Health Worker should be engaged before proceeding.

Additionally, it is important to ask permission before touching a patient and to explain the reasons why it is necessary to touch them. Always consider and address potential gender issues and establish a rapport before seeking consent.

Further information

- The Australian Commission on Safety and Quality in Health Care has developed six guides to help health service organisations improve care for Aboriginal and Torres Strait Islander consumers. Cultural competence in caring for Aboriginal and Torres Strait Islander consumers and other guides are available at <https://www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/improving-care-for-aboriginal-and-torres-strait-islander-people/>.
- The Edith Cowen University resource, Creating cultural empathy and challenging attitudes through Indigenous narratives, can be viewed at <http://altc.betterhealth.ecu.edu.au/narratives/index.php>.
- Health*Info*Net is a web portal on Aboriginal and Torres Strait Islander health topics and is available at <http://www.healthinfonet.ecu.edu.au/>.
- Refer to the Cultural Respect Framework 2016 – 2026 <http://www.coaghealthcouncil.gov.au/Portals/0/National%20Cultural%20Respect%20Framework%20for%20Aboriginal%20and%20Torres%20Strait%20Islander%20Health%202016_2026_2.pdf>.

Men's and Women's Business

Men's and Women's Business is fundamental to many Aboriginal and Torres Strait Islander cultures. Health professionals may be facing a gender-related barrier if having trouble obtaining information. Where possible, it is suggested that services are provided by a health professional of the same gender as the patient. Guidance regarding preferences should be sought directly from patients, rather than assumed.

Men's and Women's Business relates not only to patients and health professionals but also to any family, friends, Elders, community members or other support people present because it may be disrespectful to discuss gender issues in the presence of any members of the opposite gender.

Cultural safety in the context of Men's and Women's Business during healthcare can be created by:

- offering the option to see either a female or male health professional, where possible
- offering referral to an alternative service provider when a choice of male or female health professional is not possible, or offering the option of having a family member or support person present
- providing a list of options and contact details for referring patients to services where they can be seen by a professional of the preferred gender
- establishing a person's cultural preferences before discussing their health issues in the presence of members of the opposite gender
- avoiding assumptions by asking the person what could help them to feel more comfortable.

Consideration of the patient's cultural safety must include understanding that informed consent (or lack of consent) may relate to reluctance for a particular Western treatment or model of care rather than assuming any sensitivity about Men's or Women's Business.

Health literacy

Higher levels of health literacy (refer to glossary) may result in greater patient engagement with health services, improved prevention and earlier detection of cancer and therefore better clinical outcomes and superior patient experiences.

For some individuals and communities, access, participation and quality of care may be affected by:

- limited knowledge and fear about cancer, including signs and symptoms
- fear of the mainstream medical system and doubts about test accuracy and treatment efficacy
- lack of privacy and the perception of invasiveness with screening and other tests
- a cultural belief that cancer is a curse or a form of 'payback' (Treloar et al. 2013)
- limited understanding about genetic testing (for further information on genetic testing, refer to section 1.2).

Strategies to promote health literacy and improve perceptions of mainstream healthcare include:

- effective cross-cultural communication skills (refer to the *Cross-cultural communication* section for more information)
- education about using culturally sensitive information
- providing resources that are culturally appropriate and use accessible formats (for example, screening information during regular general or primary practitioner appointments, consumer guides at the time of diagnosis, supportive resources explaining genetic testing)
- engaging cancer champions or people affected by cancer to openly talk about cancer, to promote screening and seeking treatment, and to share stories about survival
- creating video tours of facilities to use as a patient education tool
- ensuring health professionals are patient-centred and take the required time to build trust
- encouraging questions through involving family and community members
- understanding tensions relating to past research exposure
- acknowledging the social determinants and cultural determinants of health
- helping people to engage in counselling.

Further information

- Health*Info*Net is a web portal on Aboriginal and Torres Strait Islander health topics and is available at <http://www.healthinfonet.ecu.edu.au/>.
- Visit the National Indigenous Cancer Network at <http://www.nican.org.au/>.
- Cancer information for Aboriginal and Torres Strait Islander people is available from Cancer Council NSW at <https://www.cancercouncil.com.au/aboriginalcancer/information-resources-for-health-workers/cancer-resources-for-patient/>.
- The NWMR Koolin Balit toolkit: Section D – Developing Aboriginal community resources is available at <http://inwpcp.org.au/toolkit-main-page/developing-culturally-responsive-and-targeted-resources/>.
- The New South Wales Department of Community Services resource, Working with Aboriginal people and communities – a practice resource, can be viewed at <http://www.community.nsw.gov.au/__data/assets/pdf_file/0017/321308/working_with_aboriginal.pdf>.
- The Cancer Institute NSW resource, Beginning the Journey – Introduction to radiation & chemotherapy treatment, can be viewed at <https://www.youtube.com/watch?v=BEYF-GOcXDc>.

Culturally appropriate resources

Using culturally appropriate resources can greatly enhance the quality of care and patient experience.

Healthcare institutions should provide culturally-specific and appropriate information in formats that are accessible for Aboriginal and Torres Strait Islander people (for example, through phone 'helplines' and brochures).

Key health professionals involved in patient care should routinely consider a patient's need for additional information and supply resources or contact information for appropriate services, as needed.

Optimal cancer care pathway

The OCPs outline the seven critical steps in the patient journey.
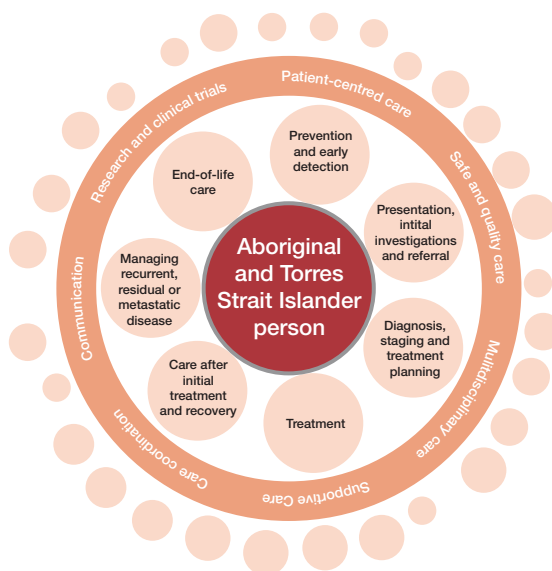
Figure 1: Patient-centred care for Aboriginal and Torres Strait Islander people

The aim of the OCP for Aboriginal and Torres Strait Islander people with cancer is to help guide system safety and responsiveness to cultural needs. Patient care does not always occur in a linear process but depends on the particular situation (such as the type of cancer, when and how the cancer is diagnosed, prognosis, management, patient decisions and the patient's physiological response to treatment).

This OCP is intended to complement the tumour-specific OCPs, acting as a tool to identify areas for health services and health professionals to improve the quality and safety of care provided to Aboriginal and Torres Strait Islander people. The information presented at each step is also complemented by the section *Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer.*

Links to the OCPs for the cancers with the greatest burden on Aboriginal and Torres Strait Islander people with respect to morbidity and mortality are provided throughout this document, and quick reference guides are presented in the *Appendix: Quick reference guides.* These cancers are breast, bowel (colorectal), liver (hepatocellular), lung, prostate and head and neck. Morbidity and mortality data is sourced from the Australian Institute of Health and Welfare webpage, Cancer in Aboriginal and Torres Strait Islander people of Australia (see <https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians-overview/contents/table-of-contents>).

To view the full clinical OCP for each tumour type, visit <www.cancer.org.au/OCP>

Step 1: Prevention and early detection

This step outlines general recommendations for providing culturally optimal health services for the prevention and early detection of cancer in Aboriginal and Torres Strait Islander people.

Compared with non-Indigenous people in Australia, Aboriginal and Torres Strait Islander people experience:

- a different pattern of cancer incidence, with some cancers occurring more frequently than among non-Indigenous people in Australia (including lung, liver, head and neck (oral) and cervical cancers) (Australian Institute of Health and Welfare 2017a, Australian Institute of Health and Welfare & Cancer Australia 2013)
- a high incidence of preventable cancers that are also more likely to be fatal, such as lung and liver cancers (Australian Institute of Health and Welfare 2017a; Cancer Australia 2015)
- higher levels of modifiable risk factors relevant to cancer, including smoking, alcohol consumption, poor diet, low levels of physical activity and high levels of infections such as hepatitis B and C (Australian Institute of Health and Welfare & Cancer Australia 2013, The Kirby Institute 2016)
- lower participation in cancer screening programs (Australian Institute of Health and Welfare & Cancer Australia 2013; Australian Institute of Health and Welfare 2018)
- a higher likelihood of having cancer at an advanced stage of development at diagnosis (Diaz et al. 2015).

Increasing access to, and participation in, preventative healthcare and cancer screening is therefore a priority for improving cancer outcomes for Aboriginal and Torres Strait Islander people.

The regular Medicare health assessment for Aboriginal and Torres Strait Islander people provides an ideal opportunity to discuss prevention and early detection, and to assess cancer risk.

Further information:

- Information on Medicare item numbers to support preventative health assessments is available at <http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Home>.
- Australian Institute of Health and Welfare information incorporates the most up-to-date data available to describe the incidence, mortality, survival and prevalence of cancer in Aboriginal and Torres Strait Islander people of Australia. It is available at <https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians-overview/contents/table-of-contents>.
- Learn more about the Medicare Benefits Schedule health assessment for Aboriginal and Torres Strait Islander people at <http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare_ATSI_mbsha_resource_kit>.
- View the National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people developed by the National Aboriginal Community Controlled Health Organisation and the Royal Australian College of General Practitioners at <http://www.racgp.org.au/your-practice/guidelines/national-guide/>.

1.1   Risk factors

While causes of cancer are not fully understood, some factors that increase the risk of developing a cancer are well recognised.

Modifiable cancer risk factors include:

- smoking
- risky alcohol consumption
- obesity and excess body fat
- physical inactivity
- certain dietary factors such as diets high in animal fat
- infections such as hepatitis B, hepatitis C and human papillomavirus (HPV).

Other non-modifiable factors associated with an increased risk of developing cancer include:

- increasing age
- a family history of cancer
- genetic factors (for example, BRCA mutation).
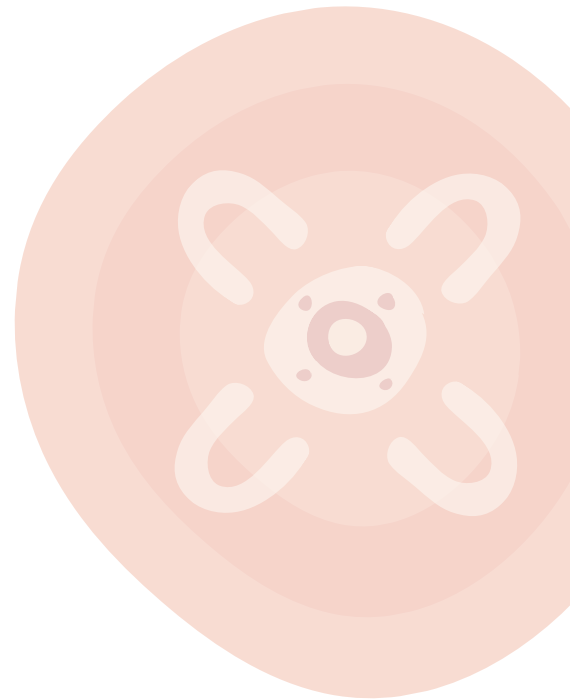
1.2 Risk reduction

About a third of the world's cancers are preventable through modifiable activity, and up to 50% are potentially preventable, including screening (World Cancer Research Fund International 2017, American Association for Cancer Research 2017).

The health gap for Aboriginal and Torres Strait Islander people is affected by social determinants and is compounded by the interaction between social determinants and risk factors (Australian Institute of Health and Welfare 2015).

Health professionals are in an ideal position to promote and advise on risk-reduction strategies relevant to the individual, taking into account any social and cultural factors. All patients should be aware of, and encouraged to optimise, their modifiable cancer risk factors.

1.2.1 Cancer risk reduction

General risk reduction advice includes:

- quitting smoking
- maintaining a healthy body weight
- being physically active, which offers benefits independently of other risk factors such as body weight management
- avoiding or limiting alcohol intake
- eating a healthy diet including plenty of vegetables, fruit and whole grains while minimising intake of red meat and processed meat, acknowledging access can be challenging in many remote areas
- reducing ultraviolet exposure
- risk-reducing medication or surgery for people with a high-risk of developing certain cancers
- completing the immunisation schedule for hepatitis B and HPV
- participating in cancer screening

1.2.2 Smoking

All current smokers should be offered smoking cessation advice and support to quit.

While the proportion of Aboriginal and Torres Strait Islander adults who smoke tobacco daily decreased between 2002 and 2012–13 from 51 per cent to 44 per cent, it remains a leading risk factor for many types of cancer (Australian Institute of Health and Welfare 2015).

Effective strategies to help people quit smoking include:

- structured interventions from health professionals, including utilising Medicare Benefits Schedule health assessment items
- individual or group counselling programs such as those offered by Quit (visit <https://www.quit.org.au/>)
- nicotine replacement therapy and other pharmacological agents.

Further information

- Find out more about the national Tackling Indigenous Smoking program at <http://www.health.gov.au/internet/main/publishing.nsf/content/indigenous-tis-lp>.

1.2.3 Immunisation

Health professionals should check that patients have completed the immunisation schedule for hepatitis B, with vaccinations at birth, two months, four months and six months (Department of Health 2015). Hepatitis B immunisation should be recommended for patients who are not currently immunised. Health professionals are also encouraged to support the uptake of HPV immunisation by boys and girls 12–13 years of age, which reduces the risk of cervical cancer and some cancers of the vagina, vulva, penis, anus, rectum and throat (Department of Health 2017a).

1.2.4 Individual assessment

For health professionals working within the primary healthcare sector, the regular Medicare health assessment for Aboriginal and Torres Strait Islander people provides an ideal opportunity to assess cancer risk.

Dental and oral hygiene workers have a role in detecting the early signs of oral cancers.

Understanding a patient's personal cancer risk level enables health professionals to recommend the most appropriate evidence-based prevention and early detection strategies. All patients should have their individual cancer risk assessed, and this will usually occur in primary care first. Cancer risk assessment should be repeated when major risk factors change (for example, new family cancer history). For patients with an increased risk of developing cancer based on their family history, consider referral to a:

- familial cancer service for further risk assessment and possible genetic testing (see below)
- specialist to plan appropriate surveillance and management.

1.2.5 Genetic testing

Particular sensitivity is required when discussing family history and genetic testing.

- It may be distressing for the patient to discuss members of the family who are part of the Stolen Generation, who are missing, or who are unknown.
- It is also important to recognise that the Aboriginal and Torres Strait Islander concept of family may include people who are not genetically related.
- Discussions of familial cancer may require a discussion of Men's Business and Women's Business in the same conversation, which may be uncomfortable for the patient.
- The patient may be asked to refer to people who have died ('Sorry Business'), which may be uncomfortable for the patient.
- The patient may be asked to either seek information about other people's cancer in the family or to consider passing information on to family members about the outcome of testing. These conversations away from the clinic may involve cultural taboos about cancer, Sorry Business and speaking about both Men's Business and Women's Business.
- The types of questions asked may cause tension relating to research exposure and so may require more information about why the questions are necessary.

Further information

- Cancer Australia's Check Your Cancer Risk online tool is available at <https://lifestylerisk. canceraustralia.gov.au/#/>.
- View the National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people developed by the National Aboriginal Community Controlled Health Organisation and the Royal Australian College of General Practitioners at <http://www.racgp.org.au/your-practice/ guidelines/national-guide/>.

1.3   Screening

All primary healthcare professionals have a responsibility to encourage participation in screening programs that are appropriate to the individual's age and risk because screening can significantly reduce mortality.

Some potentially preventable or screen-detectable cancers are more common among Aboriginal and Torres Strait Islander people than non-Indigenous people in Australia, including cancers associated with chronic infections such as hepatitis B and HPV (Australian Institute of Health and Welfare & Cancer Australia 2013; Garvey et al. 2011).

National screening programs are in place for colorectal, breast and cervical cancers. Data shows Aboriginal and Torres Strait Islander people have lower participation in screening programs than non-Indigenous people in Australia (Australian Institute of Health and Welfare 2017b; Australian Institute of Health and Welfare 2017c; Australian Institute of Health and Welfare 2017d, Australian Institute of Health and Welfare 2018, Australian Institute of Health and Welfare & Cancer Australia 2013; Binns and Condon 2006, Coory et al 2002, Roder et al. 2012, Whop et al 2016).

Increasing Aboriginal and Torres Strait Islander people's involvement with screening programs may be facilitated by:

- developing partnerships between screening programs and primary healthcare or other community-based services
- encouraging health professionals to discuss screening and immunisation with Aboriginal and Torres Strait Islander patients
- regular primary healthcare checks, including discussions and reminders about cancer screening
- promoting quality-improvement initiatives that encourage screening and primary healthcare services to use their own data, including client feedback, to inform planning and to improve access to and the quality of screening services for Aboriginal and Torres Strait Islander people (Cancer Australia 2015)
- encouraging patients to document Aboriginal and/or Torres Strait Islander status on forms. If people do not wish to identify their Aboriginal and/or Torres Strait Islander status, this must be respected.

Concerns about privacy can reduce the participation of Aboriginal and Torres Strait Islander people in screening and other health programs, particularly in regional or remote areas with smaller populations. This can be addressed by establishing rapport and trust with patients and families and reassuring people that health professionals abide by a privacy code of conduct.

Having dedicated personnel and systems to facilitate recall and reminder processes will increase participation in screening programs and timely referral to diagnostic assessment. Primary health services are strongly encouraged to work in partnership with cancer screening programs and other organisations to optimise participation, where applicable.

Further information

- Contact your local Primary Health Network or Aboriginal and Torres Strait Islander Community-Controlled Health Service to find out about local opportunities to facilitate cancer screening by visiting <http://www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Contacts> and http://www.naccho.org.au/. Note: Bowel cancer screening and breast cancer screening are not delivered through Primary Health Networks. More information on the cancer screening programs is available at <http://www.cancerscreening.gov.au/>.
- For resources about bowel screening for Aboriginal and Torres Strait Islander people visit <https://www.indigenousbowelscreen.com.au/>.
- For resources about breast screening for Aboriginal and Torres Strait Islander people visit <http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/br-campaign-indig-brochure>.
- The Australian Indigenous Health*Info*Net also provides a list of Aboriginal and Islander medical/health services at <http://www.healthinfonet.ecu.edu.au/health-infrastructure/health-workers/aboriginal-and-islander-medical-health-services>.
- View Cancer Australia's tool for Familial Risk Assessment of Breast and Ovarian Cancer (FRA-BOC) at <https://canceraustralia.gov.au/clinical-best-practice/gynaecological-cancers/familial-risk-assessment-fra-boc>.
- See Cancer Australia's position statement on over-diagnosis of breast cancer at <https://canceraustralia.gov.au/publications-and-resources/position-statements/overdiagnosis-mammographic-screening>.

1.4   Early detection

Timely diagnosis is vital for improving cancer survival. Key factors that affect detection in Aboriginal and Torres Strait Islander people include:

- limited knowledge about cancer, its symptoms and survivability
- patient concerns or fears
- limited awareness of, and access to, affordable and convenient quality health services in remote and regional areas (Cancer Australia 2014; 2015)
- comorbidities masking cancer symptoms.

Strategies for overcoming other factors that affect prevention, screening and early detection of cancer in Aboriginal and Torres Strait Islander people are addressed in the *Intent and key principles* section.

Further information

- For more information, refer to Improving the accessibility of health services in urban and regional settings for Indigenous people at <https://aifs.gov.au/publications/improving-accessibility-health-services-urban-and-regional-settings-fo>.

Tumour-specific information

For specific information about the most frequently diagnosed cancers (incidence) in Aboriginal and Torres Strait Islander people, please refer to the relevant tumour-specific OCPs:

Breast

Colorectal (bowel and rectal)

Head and neck

Hepatocellular (liver)

Lung

Prostate
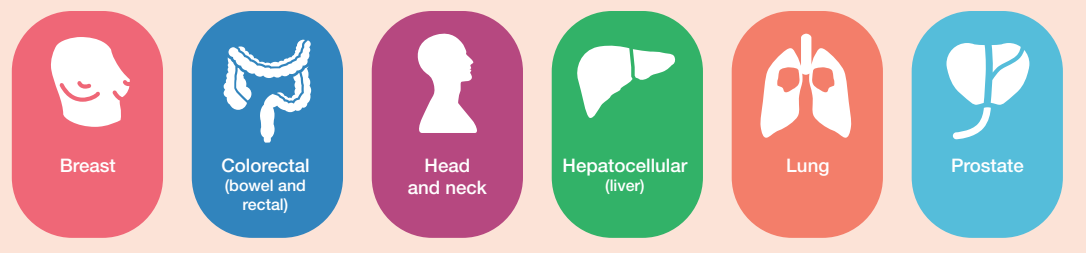
Step 2: Presentation, initial investigations and referral

This step outlines the standards of care when establishing a diagnosis and referring to other health or supportive services. The types of investigation undertaken by the general or primary practitioner depend on many factors including access to diagnostic tests, medical specialists and patient preferences.

2.1 Signs, symptoms and initial assessment

Some Aboriginal and Torres Strait Islander people may:

- present with multiple comorbidities
- have multiple risk factors (for example, obesity, smoking, a family history of cancer)
- present with a later stage of disease
- be hesitant to discuss gender-specific matters with or in the presence of a member of the opposite gender (Men's and Women's Business)
- feel culturally unsafe accessing mainstream health services
- face financial, transport or other barriers to accessing health services
- have family and community responsibilities
- experience feelings of discomfort or shame from heightened attention, sharing personal information, previous experiences or perceptions about cancer or mainstream medical services.

These factors may affect the presentation and investigative pathway, including whether the person maintains contact with health services.

2.2 Referral

If the diagnosis of cancer is confirmed or the results are inconsistent or indeterminate, referral to an appropriate specialist is warranted. Referral should include all clinical information, medical and psychosocial background, relevant family history and all images and diagnostic reports (old and new). It is important to have an interpreter and/or support person available, depending on the patient's preferences.

It is imperative for health services to ensure the patient's contact details are up to date at each visit to enable active follow-up, and that Aboriginal and/or Torres Strait Islander status has been completed. If people do not wish to identify their Aboriginal or Torres Strait Islander status, this must be respected.

Timely follow-up regarding the status of the referral is essential.

2.3 Optimal timeframes for investigations and referrals

Timeframes for completing investigations and referral to a specialist should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce a patient's distress. Additional discussions and the use of communication technologies may be required to facilitate timely discussion and involvement of family members and carers in decision making within the optimal care timelines.

Health services should designate a culturally appropriate healthcare professional to both follow up on the referral and to keep in contact with the patient to maintain engagement along the cancer pathway. The supportive and liaison role of the person's general or primary practitioner, practice team, primary health care coordinator and Aboriginal and/or Torres Strait Islander Health Worker or Health Practitioner in this process is critical.
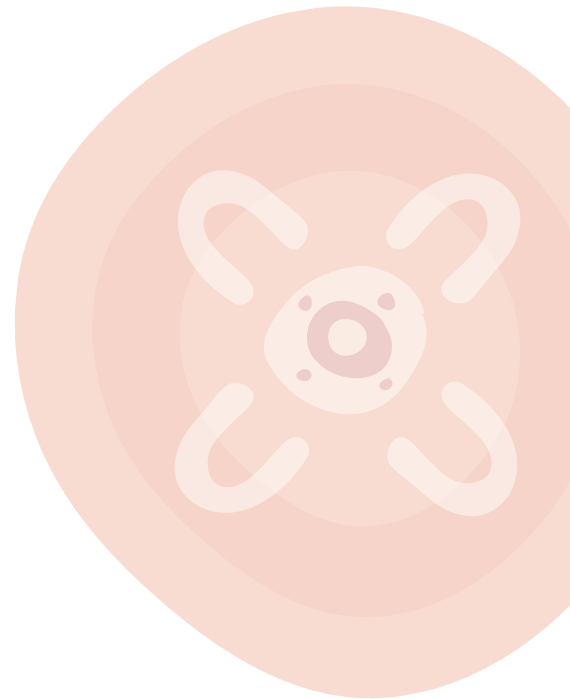
2.4 Support and communication

2.4.1 Supportive care

The supportive care needs of Aboriginal and Torres Strait Islander people with cancer and their families (including youth and children) should be identified at the time of diagnosis; however, health services should note that the need for support, such as assistance with transport and/or financial concerns, may precede a cancer diagnosis. An individualised clinical assessment is required to assess supportive care needs and should optimally be undertaken in collaboration with an Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Hospital Liaison Officer. Assessment should be repeated throughout the cancer pathway, with referrals made as required.

Access to supportive care services should be tailored to the specific social, practical and cultural needs of Aboriginal and Torres Strait Islander patients and families, including children. Remember that many Aboriginal and Torres Strait Islander people may access a wealth of support from family and the community/communities as well as local Aboriginal Community Controlled Health Service and Aboriginal Medical Services.

Note that some people may experience discomfort or shame, including shyness from the heightened attention associated with cancer investigations and follow-up or care. One avenue to minimise discomfort or shame is to invest in building a strong rapport with the person and their family/carers.

The *Supportive Care Needs Assessment Tool for Indigenous People* (SCNAT-IP) is useful for determining which support services are required by Aboriginal and Torres Strait Islander people (Garvey et al. 2016; Thewes et al. 2016).

Following the supportive care needs assessment, patients and/or their families and carers should either be directly referred to supportive services or be provided with information and contact details for the appropriate services. Follow-up to ensure patients and/or their families and carers receive the recommended support services is essential, and the responsibility for this task should be clearly assigned to a member of the care team.

Having information available about support services in the local area may also help patients to make informed decisions. Health workers should investigate options to refer or establish tailored support or rehabilitation groups to address the needs and preferences of the communities (Bainbridge et al. 2015).

Specific needs that may arise at this step of the pathway include:

- treatment for physical symptoms
- help with the emotional distress of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems, stress and adjustment difficulties, including referral to social and emotional wellbeing services and mental health services
- guidance for financial and employment issues (such as loss of income, having to deal with travel, accommodation requirements and caring arrangements for other family members)
- allied health evaluation, as appropriate.

Further information

- Learn about the SCNAT-IP at <http://www.scnatip.org/>.
- Learn about the NCCN distress thermometer at <http://edcan.org.au/edcan-learning-resources/supporting-resources/supportive-care/screening>.

### 2.4.2 Communication with the patient, family and carer

For information about communicating with patients, families and carers, refer to the *Cross-cultural communication* section.

Further information

- Find cancer information for Aboriginal and Torres Strait Islander people from Cancer Council NSW at <https://www.cancercouncil.com.au/aboriginalcancer/information-resources-for-health-workers/cancer-resources-for-patient/>.
- View the Interpretive guide to the RACGP Standards for general practices (4th edition) for Aboriginal community controlled health services at <www.racgp.org.au/your-practice/standards/interpretiveguide4thedition/>.

Tumour-specific information

For specific information about the most frequently diagnosed cancers (incidence) in Aboriginal and Torres Strait Islander people, please refer to the relevant tumour-specific OCPs:

Breast   Colorectal (bowel and rectal)   Head and neck   Hepatocellular (liver)   Lung   Prostate
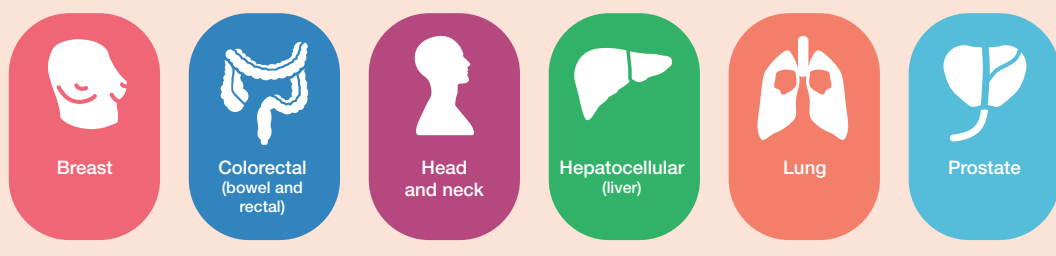
Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and planning subsequent treatment. The guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan, having considered the patient's cultural, spiritual, psychosocial and holistic needs.

Central to this step is the care coordination required to facilitate and optimise the timeline between diagnosis, staging and treatment planning for Aboriginal and Torres Strait Islander patients.

3.1   Diagnostic workup

A range of diagnostic tests, assessments and investigations should be completed at this stage of the pathway. The exact recommended diagnostic workup depends on the type of cancer involved but may include physical examinations, blood and imaging tests, and biopsies. Some procedures may require the patient to travel to receive care at a specialised centre, which could be arranged through the Patient Assistance Travel Scheme and with assistance from an Aboriginal and/or Torres Strait Islander Hospital Liaison Officer.

All patients should be assessed for medical comorbidities during the diagnostic workup.

Discussing the reason investigations are being conducted may help the person with suspected cancer to fully understand their situation and to discuss any concerns they have before providing informed consent for the diagnostic workup.

3.1.1   Timeframe for completing the diagnostic workup

Timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce a patient's distress. Making the time to facilitate access to diagnostic workups and telehealth consultations with patients and family members could optimise this pathway (especially for those living remotely).

3.2   Staging

Staging is the cornerstone of treatment planning and prognosis and should be clearly documented in the patient's medical record. Staging for many cancers is pathological following surgery because this provides the most accurate information; however, preliminary clinical staging may also be performed using laboratory and imaging tests undertaken during the diagnostic and treatment planning phase.

Details of cancer staging are outlined in each tumour-specific OCP.

Further information

- Visit the Cancer Institute of NSW's website for information about understanding the stages of cancer at <https://www.cancerinstitute.org.au/understanding-cancer/stages-of-cancer>.

3.3   Treatment planning

3.3.1   Responsibilities of the multidisciplinary team

The responsibilities of the multidisciplinary team are to:

- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided) and identify this person to the patient
- nominate a team member to coordinate patient care and identify this person to the patient
- develop and document an agreed recommended treatment plan at the multidisciplinary team meeting
- circulate the agreed multidisciplinary team treatment plan to relevant team members, including the patient's general practitioner or other primary care provider.

3.3.2   Responsibilities of individual team members

The general or primary medical practitioner who made the referral is responsible for the patient until care is transferred to another practitioner.

The general or primary medical practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment and coordination and continuity of care, as well as providing information and support to the patient and their family and carers. For Aboriginal and Torres Strait Islander patients, a primary health care coordinator may have a key role.

The cancer care coordinator is responsible for ensuring there is continuity throughout the care process and for coordinating all necessary clinical care for a particular phase. The cancer care coordinator may change over the course of the pathway. If a cancer care coordinator is not available, this responsibility should be assigned to another team member. Effective care coordination is a key factor for enhancing Aboriginal and Torres Strait Islander patient experiences and for promoting ongoing engagement with health services.

The lead clinician is responsible for overseeing the activity of the team and for clearly explaining the purpose of the multidisciplinary team meeting(s) to the patient in a culturally safe way.

An Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Hospital Liaison Officer should oversee care to ensure it is culturally appropriate and provide emotional, social and cultural support to patients, their families and carers.

3.3.3 Members of the multidisciplinary team

The multidisciplinary team should comprise the core disciplines that are integral to providing best practice and relevant expertise for the specific cancer type. Team membership may also vary according to the stage of disease being treated and the individual needs of the patient but should reflect both clinical and psychosocial aspects of care (Department of Health and Human Services 2007a). For Aboriginal and Torres Strait Islander patients, it is essential that the team includes an expert in providing culturally appropriate care to this population. This may be an Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Hospital Liaison Officer.

Access to multidisciplinary team members with the required expertise may require coordination with specialty centres.

3.3.4 The optimal timing for multidisciplinary team planning

All newly diagnosed patients should be discussed in a multidisciplinary team meeting. In some situations, this may be facilitated with telehealth technology. The level of discussion may vary depending on both clinical and psychosocial factors.

Results of all relevant tests, imaging and assessment of comorbidities should be available for the multidisciplinary team discussion. The care coordinator or treating clinician should also present information about the patient's concerns, preferences and social circumstances at the meeting (Department of Health and Human Services 2007b).

3.4 Research and clinical trials

All patients should be offered the opportunity to participate in a clinical trial or clinical research if appropriate. Cross-referral between clinical trials centres should be encouraged to facilitate participation. Use of telehealth technology such as the Australasian Tele-trial Model may also improve access to trials.

All clinical trials conducted in Australia must fulfil specific criteria to receive approval from a human research ethics committee. These requirements include addressing issues that may affect Aboriginal and Torres Strait Islander people such as research design, culture, language and ethics. Further, research focused on diseases identified as being of specific concern to Aboriginal and Torres Strait Islander people, such as for the cancers with the greatest burden in these populations, must provide fair opportunity for Aboriginal and Torres Strait Islander people to participate (National Health and Medical Research Council 2003; National Health and Medical Research Council et al. 2007). Accordingly, health professionals should routinely offer to refer all patients to relevant clinical trials, including Aboriginal and Torres Strait Islander patients, as appropriate.

To achieve equity in the participation rate of Aboriginal and Torres Strait Islander people in clinical trials, clinicians should use culturally appropriate resources to better explain the benefits of the clinical trials.

Further information

- Australian Cancer Trials is a national clinical trials database that provides information on the latest clinical trials including trials that are recruiting new participants. For more information visit <http://www.australiancancertrials.gov.au/>.

- See the National Health and Medical Research Council's Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research at <https://www.nhmrc.gov.au/guidelines-publications/e52> and Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics at <https://www.nhmrc.gov.au/guidelines-publications/e65>.

- The National Health and Medical Research Council's National statement on ethical conduct in human research is available at <https://www.nhmrc.gov.au/guidelines-publications/e72>.

- Learn about the Australasian Tele-trial Model at <https://www.cosa.org.au/media/332325/cosa-teletrial-model-final-19sep16.pdf>.
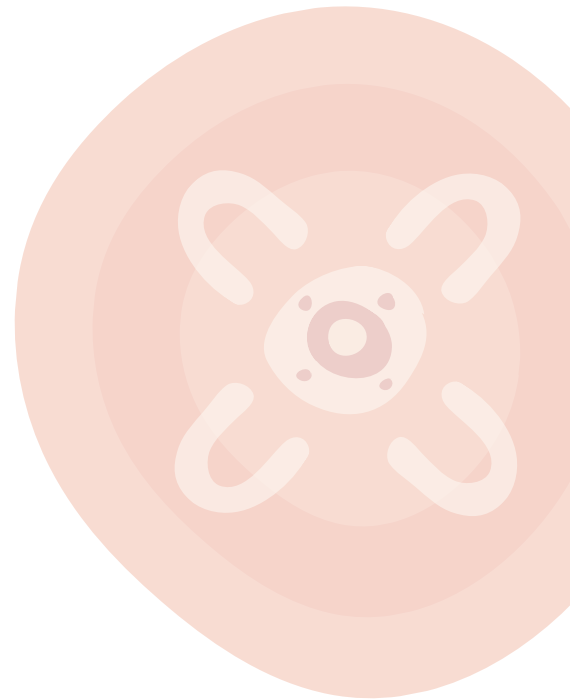
3.5   Support and communication

3.5.1   Supportive care

An individualised clinical assessment is required to assess and meet the needs of people with cancer, their families and carers; referral should be as required. Refer to section 2.4.1 for detailed information about providing supportive care to Aboriginal and Torres Strait Islander people affected by cancer.

3.5.2   Communication with the patient, family and carer

In addition to the key points outlined in the *Cross-cultural communication* section, the lead clinician should:

- establish if the patient has a regular or preferred general or primary practitioner
- provide the contact details of a key contact person for the patient
- discuss a timeframe for diagnosis and treatment with the patient and carer
- discuss the benefits of multidisciplinary care, and make the patient aware that their health information will be available to the team for the discussion at multidisciplinary team meetings
- offer individualised tumour-specific information that meets the needs of the patient and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information and support from websites, community and national cancer services and support groups for both patients and carers
- use a professionally trained interpreter if required
- provide the patient and carer with the contact details of the care coordinator and the appropriate treatment team member
- be open to and encourage discussion about the diagnosis, prognosis and survivorship while considering the patient's personal and cultural beliefs and expectations, and their ability to comprehend the communication.

It is essential that effective communication is achieved before patients can provide informed consent for medical procedures. If there are any concerns about comprehension or establishing a two-way dialogue with Aboriginal and Torres Strait Islander patients, the services of a medically trained interpreter and/or an Aboriginal and/or Torres Strait Islander Hospital Liaison Officer or Health Worker should be engaged before proceeding.

### 3.5.3 Communication with the general practitioner

The lead clinician should ensure regular and timely (within a week) communication with the person's general or primary practitioner or primary care provider regarding the treatment plan and recommendations from multidisciplinary team and should invite the general or primary practitioner to participate in multidisciplinary team meetings. Where appropriate, this may involve using video- or teleconferencing.

The lead clinician should:

- ensure regular and timely (within a week) communication with the person's general or primary practitioner or primary care provider regarding the treatment plan and recommendations from the multidisciplinary team
- notify the general or primary practitioner, Aboriginal and/or Torres Strait Islander Health Worker or Hospital Liaison Officer and family/carer if the person does not attend clinic appointments
- gather information from the general or primary practitioner including their perspective on the person (psychological issues, cultural preferences, social issues and comorbidities) and locally available support services
- contribute to the development of a chronic disease and mental healthcare plan as required
- discuss management of shared care
- invite the general or primary practitioner to participate in multidisciplinary team meetings (consider using video or teleconferencing).

Tumour-specific information

For specific information about the most frequently diagnosed cancers (incidence) in Aboriginal and Torres Strait Islander people, please refer to the relevant tumour-specific OCPs:

Breast	Colorectal (bowel and rectal)	Head and neck	Hepatocellular (liver)	Lung	Prostate
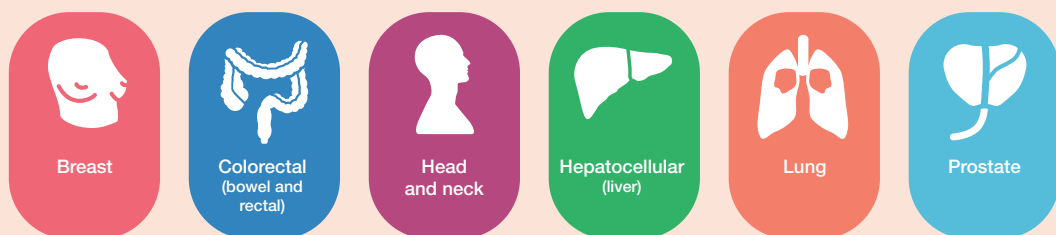
Step 4: Treatment

Step 4 outlines the optimal treatment pathway and addresses the key aspects of care that should be kept in mind while providing treatment for Aboriginal and Torres Strait Islander people with cancer.

4.1 Treatment intent

The intent of treatment can be defined as one of the following:

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

The morbidity and risks of treatment need to be balanced against the potential benefits.

The lead clinician should discuss treatment intent and prognosis with the patient and carer prior to beginning treatment.

If appropriate, advance care planning should be initiated with patients and their carers at this stage. Advance care planning can deliver multiple benefits such as ensuring a person's preferences are known and respected after the loss of decision-making capacity (Australian Health Ministers' Advisory Council 2011).

4.2 Treatment options

The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the patient.

Aboriginal and Torres Strait Islander perception and view of health, illness and treatment may affect decision making. When discussing treatment options with the patient and carer/support person, the lead clinician should consider:

- the timing and duration of treatment
- travel and accommodation needs
- possible work, caring or education commitments
- cost
- cultural obligations, including family and community
- engagement with identified health professionals such as an Aboriginal and/or Torres Strait Islander Health Worker or Hospital Liaison Officer and/or interpreter services
- providing culturally appropriate resources to support decision making
- the involvement of spiritual advisors, traditional healers and traditional medicine (refer to section 4.6).

Referral to specialised centres and/or the use of teleoncology technology may be considered to facilitate access to the recommended treatment options outlined in the tumour-specific OCPs.

Further information

- View the Cancer Council's *Making decisions about treatment* resource for Aboriginal and Torres Strait Islander people at <https://www.cancercouncil.com.au/wp-content/uploads/2010/10/making_decisions_CAN3232.pdf>.
- See the Clinical Oncology Society of Australia's Clinical practice guidelines for teleoncology at <http://wiki.cancer.org.au/australia/COSA:Teleoncology>.

4.3   Optimal timeframes for treatment

Timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce a patient's distress. Additional discussions and use of communication technologies may be required to facilitate timely discussion and involvement of family members and carers in decision making.

4.4   Palliative care

Early referral, access to and uptake of good-quality and culturally appropriate palliative care services can improve the quality of life for people with cancer and in some cases may be associated with survival benefits (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014).

The lead clinician should ensure all patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis. Communication about the value of palliative care in improving symptom management and quality of life should be emphasised to patients and their carers.

Health professionals initiating discussions with patients about future care needs may be assisted by the Aboriginal and Torres Strait Islander version of the *Dying to talk* resource (see *Further information* below). Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (Australian Health Ministers' Advisory Council 2011). When discussing death or dying with Aboriginal and Torres Strait Islander people, the terms 'passing', 'not going to get better' or 'returning to Country' may be more accepted due to spiritual beliefs around the life cycle.

Further guidance regarding palliative care is provided in detail in Step 7 of the pathway.

Further information

- Refer to the Aboriginal and Torres Strait Islander version of Dying to talk at <http://dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter/>.
- Refer to the Aboriginal and Torres Strait Islander people palliative care resource kit at <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm>.
- View the Queensland Health resource Sad news, sorry business at <https://www.health.qld.gov.au/__data/assets/pdf_file/0023/151736/sorry_business.pdf>.
- Refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.
- Refer to advance care planning resources at <https://www.advancecareplanning.org.au/for-health-and-care-workers/in-various-settings/advance-care-planning-in-aboriginal-and-torres-strait-islander-populations>.

4.5 Research and clinical trials

All patients should be offered the opportunity to participate in a clinical trial or clinical research if appropriate. Refer to section 3.4 for more detailed information.

Further information

- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <http://www.australiancancertrials.gov.au/>.
- See the National Health and Medical Research Council's Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research at <https://www.nhmrc.gov.au/guidelines-publications/e52> and Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics at <https://www.nhmrc.gov.au/guidelines-publications/e65>.
- The National Health and Medical Research Council's National statement on ethical conduct in human research is available at <https://www.nhmrc.gov.au/guidelines-publications/e72>.

4.6 Traditional medicine, complementary therapies and alternative therapies

Many Aboriginal and Torres Strait Islander traditional medicine and healing practices (also referred to as 'bush medicine') are currently used throughout Australia. Traditional medicine may be used in conjunction with mainstream medicine (such as for symptom relief from chemotherapy or stress encountered by people with cancer), in place of mainstream medicine or not at all, depending on the patient's personal situation and beliefs (Shahid et al. 2010). Some Aboriginal and Torres Strait Islander people may use traditional medicine not only as a means for cancer treatment or symptom relief but also to maintain a connection with their culture, ancestors and spirituality (Shahid et al. 2010). The lead clinician should explore the patient's reason for using complementary or alternative medicine (CAM) therapies and the evidence base.

It should be noted that Australia currently lacks policies regarding the use of Aboriginal medicine; therefore, there are no established accreditation, qualification or registration processes for traditional healers.

Many alternative therapies and some traditional and complementary therapies have not been assessed for efficacy or safety. Some have been studied and found to be harmful or ineffective (Cancer Australia 2010). Referral to another health professional with expertise in the field of CAM (for example, a clinical pharmacist, medical practitioner, nurse, nutritionist, psychologist or social worker) may assist patients to reach an informed decision about their CAM use (Clinical Oncology Society of Australia 2013).

The lead clinician should discuss and document in the medical records the patient's use (or intended use) of traditional or CAM therapies not prescribed by the multidisciplinary team to identify any potential toxicity or drug interactions, particularly when plant-based therapies are involved. It is an advantage to all concerned if patients are able to discuss CAM therapies openly, secure in the knowledge that they will continue to receive support and understanding from their treatment team (Cancer Australia 2010).

See the Glossary for complete definitions of traditional medicine and CAM therapies.

Further information

- See Cancer Australia's position statement on complementary and alternative therapies at <http://canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>.
- See the Clinical Oncology Society of Australia's position statement at <www.cosa.org.au/publications/position-statements.aspx>.
- The NUTTAB 2010 online searchable database includes nutrient profiles for six Australian native foods at <https://www.foodstandards.gov.au/science/monitoringnutrients/nutrientables/nuttab/Pages/default.aspx>.

4.7 Pain management

Effective pain management requires an appreciation and respect of cultural perspectives regarding pain. A lack of request for pain relief should not be interpreted as a lack of need.

Aboriginal and Torres Strait Islander patients may not actively report pain or other needs (McGrath 2006); therefore, the lead clinician should be proactive about determining the appropriate time for referral to palliative care for symptom control.

Effective strategies to manage pain for Aboriginal and Torres Strait Islander people include:

- being proactive about offering patients pain relief
- offering the option for patients to discuss their pain and pain management with a health professional of the same gender, wherever possible
- using oral pain relief options if preferred by the patient, where appropriate
- developing and/or using a pain tool that is culturally appropriate for the local community
- fully explaining the options, usage and side effects of pain relief
- providing information about services that can assist with pain management or further questions, particularly when pain management is happening outside of the hospital environment.

Further guidance regarding pain management is provided in detail in step 7 of the pathway.

Further information

- Refer to the Poche Health Best evidence summary for pain management at <http://pochehealth. edu.au/best-evidence-summary-for-pain-management/>.

4.8 Support and communication

4.8.1 Supportive care

An individualised clinical assessment is required to assess and meet the needs of people with cancer, their families and carers; referral should be as required. The supportive care requirements for cancer patients vary significantly between tumour types, stage of disease and different populations. As such, providers need to be responsive and reassess individual patients' needs at each step of the cancer pathway.

Refer to section 2.4.1 for detailed information about providing supportive care to Aboriginal and Torres Strait Islander people affected by cancer.

Further information

- Learn about the SCNAT-IP at <http://www.scnatip.org/>.
- Learn about the NCCN distress thermometer at <http://edcan.org.au/edcan-learning-resources/ supporting-resources/supportive-care/screening>.

4.8.2 Communication with the patient, family and carer

In addition to the key points outlined in the *Cross-cultural communication* section, the lead clinician should discuss the treatment plan with the patient and carer, including the intent of treatment and expected outcomes, and provide a written copy or other accessible form of the plan. This should include the potential side effects and what can be done about them, and the prognosis. The lead clinician should also provide the patient and carer with information on the possible side effects of treatment, self-management strategies and emergency contacts.

4.8.3 Communication with the general practitioner

The lead clinician should ensure regular and timely two-way communication with the patient's general practitioner regarding:

- their role in symptom management, psychosocial care and referral to local services
- the treatment plan, including intent and potential side effects
- supportive and palliative care requirements
- the patient's prognosis and their understanding of this
- enrolment in research or clinical trials
- changes in treatment or medications
- recommendations from the multidisciplinary team.

Tumour-specific information

For specific information about the most frequently diagnosed cancers (incidence) in Aboriginal and Torres Strait Islander people, please refer to the relevant tumour-specific OCPs:

| Breast | Colorectal (bowel and rectal) | Head and neck | Hepatocellular (liver) | Lung | Prostate |
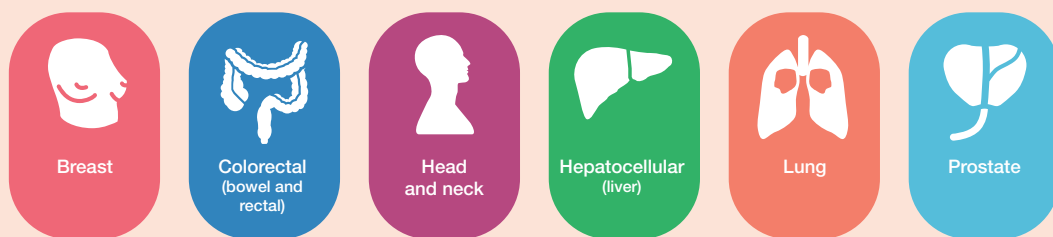
Step 5: Care after initial treatment and recovery

The transition from active treatment to post-treatment care is critical to long-term health. After completing initial treatment, patients should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the multidisciplinary team. Transition from acute to primary or community care will vary depending on the type and stage of cancer, and needs to be planned. In some cases, patients will require ongoing, hospital-based care.

5.1   Survivorship

During the survivorship phase people affected by cancer often face issues that are different from those experienced during active treatment for cancer. International research shows there is an important need to focus on helping people with cancer to cope with life beyond their acute treatment.

Many people with cancer experience persisting side effects at the end of treatment. Emotional and psychological issues include distress, anxiety, depression, cognitive changes and fear of cancer recurrence. Late effects may occur months or years later and are dependent on the type of cancer treatment. People who have or have had cancer may experience altered relationships and may encounter practical issues, including difficulties with returning to work or study, and financial hardship.

For Aboriginal and Torres Strait Islander people, healing and culture are inextricably linked. The pathway to healing is through cultural activity. Reinstating pride in cultural identity, connection to Country and involvement in community are critical elements of traditional healing programs (Australian Indigenous Health*Info*Net 2016).

It is important to consider additional support a person may need if they are returning to an environment that does not support a healthy lifestyle, coupled with the limited ability to improve lifestyle due to the social determinants of health.

People affected by cancer need to see a specialist for regular follow-up, often for five or more years after their cancer treatment finishes. In its report, *From cancer patient to cancer survivor: Lost in transition*, the US-based Institute of Medicine describes four essential components of survivorship care (Institute of Medicine & National Research Council 2006).

- the prevention of recurrent and new cancers, as well as late effects
- surveillance for cancer recurrence or second cancers, and screening and assessment for medical and psychosocial late effects
- interventions to deal with the consequences of cancer and cancer treatments (including managing symptoms, distress and practical issues)
- coordination of care between all providers to ensure the patient's needs are met.

There are particular challenges for remote patients in accessing specialists for follow-up after cancer treatment finishes. At rural and remote health clinics, unscheduled reviews may involve multiple steps to organise and can be influenced by outreach assessment and appointment wait times. Cultural obligations may affect when a patient can attend a specialist appointment, which may delay timely investigations and any subsequent treatment.
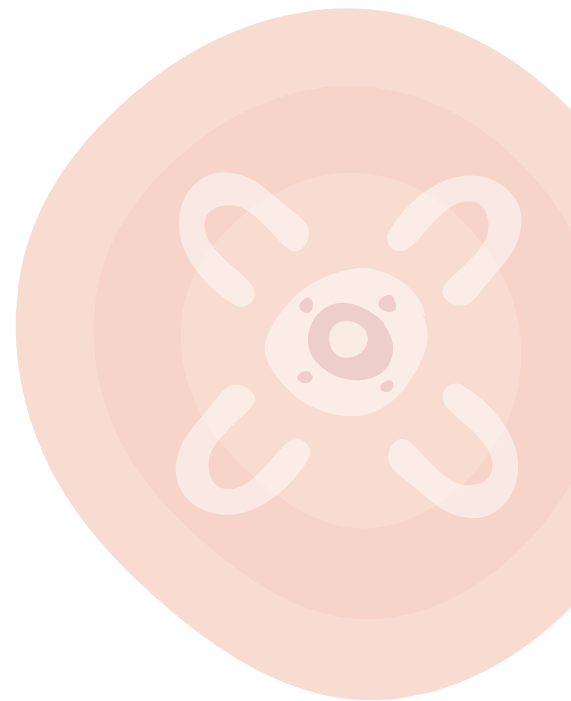
Strategies to assist Aboriginal and Torres Strait Islander people affected by cancer with the transition to survivorship include:

- engaging Aboriginal and/or Torres Strait Islander Health Workers, Health Practitioners, the Primary Healthcare Coordinator and/or Hospital Liaison Officer to support transition after treatment ends
- providing culturally appropriate resources about healthy lifestyle choices
- patient education about managing their own health needs
- information about relevant available services, and how they can be accessed
- a discussion with patients about their beliefs and definition of living well to ensure health services are working towards the patient's ideal outcome
- developing collaborative partnerships between Aboriginal and Torres Strait Islander communities and health services that specifically address cancer survivorship
- offering referral pathways to social and emotional wellbeing services and mental health services.

Further information

- Access the Clinical Oncology Society of Australia Model of Survivorship care at <https://www.cosa.org.au/groups/survivorship/resources/>.
- Access the Cancer Australia Principles of Cancer Survivorship at <https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/principles-cancer-survivorship>.
- Access the Aboriginal and Torres Strait Islander Healing Portal at <http://www.healthinfonet.ecu.edu.au/related-issues/healing>.

5.2   Post-treatment care planning

5.2.1 Treatment summary

When the initial treatment is finished, the patient, the patient's carer (as appropriate) and general practitioner or primary care provider should receive a treatment summary outlining:

- the diagnostic tests performed and results
- tumour characteristics
- the type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers, including Aboriginal and/or Torres Strait Islander Health Workers.

5.2.2 Follow-up care

Care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence, developing late effects and psychological issues) as well as individual clinical and supportive care needs. It is important that post-treatment care is evidence-based and consistent with guidelines.

Having dedicated personnel responsible for setting up regular and timely recalls and follow-up appointments can greatly assist with providing optimal follow-up care.

Responsibility for follow-up care should be agreed between the lead clinician, the person's general or primary practitioner, relevant members of the multidisciplinary team (including any relevant care coordinator) and the patient, resulting in a follow-up care plan that outlines:

- what medical follow-up is required (surveillance for cancer spread, recurrence or secondary cancers, screening and assessment for medical and psychosocial effects)
- care plans from other health professionals to manage the consequences of the cancer and treatment
- potential barriers to the follow-up plan (such as transport and cost issues) and strategies or referrals to support services to address these
- instructions for how to gain rapid re-entry to specialist medical services for suspected recurrence.

For patients being managed, rather than cured, the plan should address:

- the role of follow-up for patients, which is to evaluate tumour control, monitor and manage symptoms from the tumour and treatment and provide psychological support
- that they will be retained within the multidisciplinary team management framework.

In particular circumstances, follow-up care can safely and effectively be provided:

- in the primary care setting
- by other suitably trained staff (for example, nurse-led follow-up)
- in a non-face-to-face setting (for example, by telehealth).

The options for follow-up should be discussed when primary treatment is completed and should prioritise the patient's preferences regarding the choice of health professional and/or location of the follow-up care, where possible.

Further information

- Refer to the Aboriginal and Torres Strait Islander people palliative care resource kit at <http:// webarchive.nla.gov.au/gov/20140801064435/http://www.health.gov.au/internet/main/publishing. nsf/Content/palliativecare-pubs-indig-resource.htm>.
- View the Queensland Health resource Sad news, sorry business at <https://www.health.qld.gov. au/__data/assets/pdf_file/0023/151736/sorry_business.pdf>.
- Refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

5.3   Research and clinical trials

All patients should be offered the opportunity to participate in a clinical trial or clinical research if appropriate. Refer to section 3.4 for more detailed information.

Further information

- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <http://www.australiancancertrials.gov.au/>.

- See the National Health and Medical Research Council's Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research at <https://www.nhmrc.gov.au/guidelines-publications/e52> and Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics at <https://www.nhmrc.gov.au/guidelines-publications/e65>.

- The National Health and Medical Research Council's National statement on ethical conduct in human research is available at <https://www.nhmrc.gov.au/guidelines-publications/e72>.

5.4   Support and communication

5.4.1 Supportive care

An individualised clinical assessment is required to assess and meet the needs of people with cancer, their families and carers; referral should be as required. Refer to section 2.4.1 for detailed information about providing supportive care to Aboriginal and Torres Strait Islander people affected by cancer.

Specific needs relevant to survivorship may include the following.

Physical needs

- Weight changes may require referral to a dietitian before, during and after treatment.
- Altered sexual interest and sexual dysfunction may require referral to a clinician skilled in this area.
- Patients may need support to cope with hair loss.
- Additional help in adopting healthy lifestyle behaviours might be required.

Psychological needs

- Emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns may need attention.
- Anxiety/depression, interpersonal problems, stress and adjustment difficulties may require referral to a counsellor or mental health professional.

Social/practical needs

- Difficulties with returning to work or study may require extra support.
- Increased community support may be required as the patient recovers from treatment.

Further information

- Learn about the SCNAT-IP at < www.scnatip.org>.
- Learn about the NCCN distress thermometer at <http://edcan.org.au/edcan-learning-resources/supporting-resources/supportive-care/screening>.

5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway, from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae. When assessing the need for rehabilitation, health professionals should ask questions to understand the patient's lifestyle and what living well means to them, to make sure the recovery plan addresses their personal priorities.

5.4.3 Communication with the patient, carer and family

In addition to the key points outlined in the *Cross-cultural communication* section, the general or primary practitioner should:

- consider that the term 'survivor' may have negative connotations for Aboriginal and Torres Strait Islander people for historical reasons
- discuss the management of any of the issues identified in section 5.4.1
- explain the treatment summary and follow-up care plan
- provide culturally appropriate information about the signs and symptoms of recurrent disease, secondary prevention and healthy living.

5.4.4 Communication with the general practitioner

The lead clinician should ensure regular, timely, two-way communication with the patient's general practitioner (or other regular care provider) regarding:

- the follow-up care plan
- potential late effects
- supportive care requirements
- the patient's progress
- recommendations from the multidisciplinary team
- any shared care arrangements
- a process for rapid re-entry to medical services for patients with suspected recurrence.

Tumour-specific information

For specific information about the most frequently diagnosed cancers (incidence) in Aboriginal and Torres Strait Islander people, please refer to the relevant tumour-specific OCPs:

Breast   Colorectal (bowel and rectal)   Head and neck   Hepatocellular (liver)   Lung   Prostate
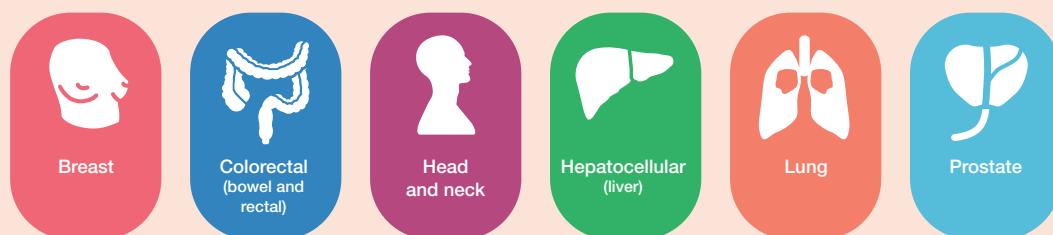
Step 6: Managing recurrent, residual or metastatic disease

Step 6 is concerned with managing cancer recurrence or progression and/or metastatic disease.

6.1   Signs and symptoms of recurrent, residual or metastatic disease

Some patients will present with symptoms of recurrent, progressive or metastatic disease. Some cases of recurrent, progressive or metastatic disease will be detected by routine follow-up in a person who is asymptomatic.

6.2   Role of the multidisciplinary team

There should be timely referral to the original multidisciplinary team (where possible), with referral on to a specialist centre for recurrent or metastatic disease, as appropriate. Where relevant, the multidisciplinary team should include an expert in providing culturally safe and responsive care (refer to section 3.3.3).

6.3   Treatment

Treatment will depend on the type, location and extent of the disease, as well as the previous management and the patient's performance status and preferences. The patient should be reassessed at a multidisciplinary team meeting, and treatment may include all modalities of care. The care plan may involve a combination of clinical and supportive therapies. Referral to specialised centres and/or the use of teleoncology technology may be considered to facilitate access to the optimal treatment options.

The morbidity and risks of treatment need to be balanced against the potential benefits.

The intent of treatment may be curative, to improve quality and/or length of life or to provide symptom palliation. To allow the patient to make informed decisions, health professionals need to ensure the patient and their carers receive culturally appropriate information on the stage of disease and the treatment options available.

Advance care planning should be initiated. Advance care planning can deliver multiple benefits such as ensuring a person's preferences are known and respected, should their decision-making capacity be lost (Australian Health Ministers' Advisory Council 2011). Health professionals should note that when discussing death or dying with Aboriginal and Torres Strait Islander people, the terms 'passing', 'not going to get better' or 'returning to Country' may be more accepted due to spiritual beliefs around the life cycle. Obtain guidance about passing from the Aboriginal and/or Torres Strait Islander Health Worker, Hospital Liaison Officer or relevant identified health professional and ensure patients understand their prognosis and treatment.

6.4   Pain management

Effective pain management requires an appreciation and respect of cultural perspectives regarding pain. Care should be taken to avoid stereotyping of Aboriginal and Torres Strait Islander people. However, a lack of request for pain relief should not be interpreted as a lack of need. Refer to section 4.7 for more detailed information.

6.5   Palliative care

Early referral, access to and uptake of good-quality and culturally appropriate palliative care services can improve the quality of life for people with cancer and in some cases may be associated with survival benefits (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). Refer to section 4.4 for more detailed information.

Further information

- Refer to the Aboriginal and Torres Strait Islander people palliative care resource kit at <http://webarchive.nla.gov.au/gov/20140801064435/http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm>.
- View the Queensland Health resource Sad news, sorry business at <https://www.health.qld.gov.au/__data/assets/pdf_file/0023/151736/sorry_business.pdf>.
- Refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.
- Refer to advance care planning resources at <https://www.advancecareplanning.org.au/for-health-and-care-workers/in-various-settings/advance-care-planning-in-aboriginal-and-torres-strait-islander-populations>.

6.6   Research and clinical trials

All patients should be offered the opportunity to participate in a clinical trial or clinical research if appropriate. Refer to section 3.4 for more detailed information.

Further information

- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <http://www.australiancancertrials.gov.au/>.
- See the National Health and Medical Research Council's Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research at <https://www.nhmrc.gov.au/guidelines-publications/e52> and Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics at <https://www.nhmrc.gov.au/guidelines-publications/e65>.
- The National Health and Medical Research Council's National statement on ethical conduct in human research is available at <https://www.nhmrc.gov.au/guidelines-publications/e72>.

6.7　Support and communication

6.7.1　Supportive care

An individualised clinical assessment is required to assess and meet the needs of people with cancer, their families and carers; referral should be as required. Refer to section 2.4.1 for detailed information about providing supportive care to Aboriginal and Torres Strait Islander people affected by cancer.

Further information

- Learn about the SCNAT-IP at <www.scnatip.org>.
- Learn about the NCCN distress thermometer at <http://edcan.org.au/edcan-learning-resources/supporting-resources/supportive-care/screening>.
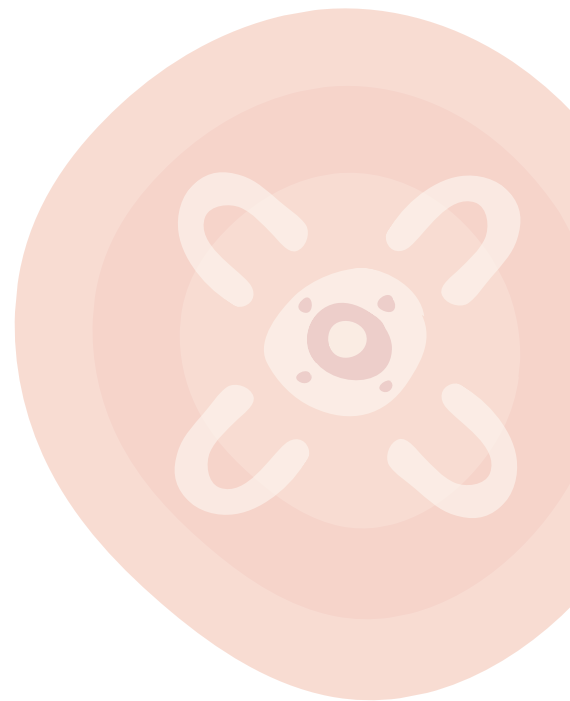
6.7.2 Rehabilitation

Rehabilitation may be required at any point of the care pathway, from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae. When assessing the need for rehabilitation, health professionals should ask questions to understand the patient's lifestyle and what living well means to them, to make sure the recovery plan addresses their personal priorities.

6.7.3 Communication with the patient, carer and family

The lead clinician should ensure there is adequate discussion with the patient and their family/carer about the diagnosis and recommended treatment including the intent of treatment and possible outcomes, the likely adverse effects and the supportive care options available.

Initiate a discussion regarding advance care planning with the patient and their family/carer, if appropriate.

Further information

- Refer to the Aboriginal and Torres Strait Islander version of Dying to talk at <http://dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter/>.
- Refer to the Aboriginal and Torres Strait Islander people palliative care resource kit at <http://webarchive.nla.gov.au/gov/20140801064435/http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm>.
- View the Queensland Health resource Sad news, sorry business at <https://www.health.qld.gov.au/__data/assets/pdf_file/0023/151736/sorry_business.pdf>.
- Refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

Tumour-specific information

For specific information about the most frequently diagnosed cancers (incidence) in Aboriginal and Torres Strait Islander people, please refer to the relevant tumour-specific OCPs:

Breast

Colorectal (bowel and rectal)

Head and neck

Hepatocellular (liver)

Lung

Prostate

Step 7:   End-of-life care

Engagement with culturally appropriate palliative care services can improve the experiences of Aboriginal and Torres Strait Islander people affected by cancer, as well as those of their families and carers. Communication about the value of palliative care in improving symptom management and quality of life should be emphasised to patients and their carers.

End-of-life care is appropriate when the person's symptoms are increasing and functional status is declining. Step 7 is concerned with maintaining the person's quality of life and addressing their health, supportive and spiritual care needs as they approach the end of life, as well as the needs of their family and carers. The principles of a palliative approach to care need to be shared by the multidisciplinary team when making decisions with the patient, their family and carers.

7.1   Multidisciplinary palliative care

If not already organised, a referral to palliative care services should be considered at this stage, including nursing, spiritual care, palliative medicine specialist backup, inpatient palliative bed access (as required), social work and bereavement counselling. This should involve engaging with the patient's general or primary practitioner or other primary health professionals such as an Aboriginal and Torres Strait Islander community-controlled health service. The multidisciplinary palliative care team should include an expert in providing culturally safe and responsive care to Aboriginal and Torres Strait Islander people such as an Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Hospital Liaison Officer.

The multidisciplinary palliative care team may consider seeking additional expertise from:

- pain specialists
- pastoral carers or spiritual advisors
- traditional healers
- bereavement counsellors
- Elders and Aboriginal and/or Torres Strait Islander health professionals
- therapists (for example, music or art)
- a respite specialist
- home- and community-based care
- specialist community palliative care workers
- community nursing
- other appropriate supportive care services (such as transport or financial assistance) to facilitate home care, where applicable.

Improved access to palliative care services may be facilitated by:

- ensuring health professionals understand the importance and benefits of timely referral to palliative care services
- involving home communities and family in the planning and delivery of palliative care services
- developing and/or providing culturally appropriate resources about palliative care services.

If not already in place, the patient and carer should be encouraged to develop an advance care plan (Australian Health Ministers' Advisory Council 2011). When discussing death or dying with Aboriginal and Torres Strait Islander people, the terms 'passing', 'not going to get better' or 'returning to Country' may be more accepted due to spiritual beliefs around the life cycle.

The multidisciplinary palliative care team should identify who will act as the lead health professional and communicate with the patient and their family and carers to develop the advance care plan, addressing:

- the patient's needs and preferences regarding the cultural aspects of their care
- the most appropriate place of care and preferred place of death (addressed in further detail in section 7.1.1)
- who the appropriate person within the family is to provide care and consent and to make funeral arrangements
- requirements for cultural ceremonies and practices, such as outdoor spaces.

If the patient is being cared for in a health service environment, policies regarding the number of visitors allowed at one time and/or visiting hours may need to be relaxed.

Wherever possible and requested by the patient and/or their family or carers, health services should support the inclusion of cultural practices, which may include the services of a spiritual advisor, traditional healer or Elders, access to traditional foods, and performing ceremonies. For example, in some Aboriginal and Torres Strait Islander communities, there are certain ceremonies (such as a smoking ceremony) that need to be performed at the site of the death before it can be used again, or the place of death may need to be vacated or avoided for a period of time.

Ensure carers and families receive information, support and guidance regarding their role according to the patient's needs and wishes (Palliative Care Australia 2005).

Further information

- Refer to the Aboriginal and Torres Strait Islander version of Dying to talk at <http://dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter/>.
- Refer to the Aboriginal and Torres Strait Islander people palliative care resource kit at <http://webarchive.nla.gov.au/gov/20140801064435/http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm>.
- View the Queensland Health resource Sad news, sorry business at <https://www.health.qld.gov.au/__data/assets/pdf_file/0023/151736/sorry_business.pdf>.
- Refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.
- Refer to advance care planning resources at <https://www.advancecareplanning.org.au/for-health-and-care-workers/in-various-settings/advance-care-planning-in-aboriginal-and-torres-strait-islander-populations>.
- View Palliative Care Australia's position statement at <http://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Palliative-care-and-Indigenous-Australians-position-statement-updated-16-8-11.pdf>.
- The Program of Experience in the Palliative Approach (PEPA) provides education and training about the palliative approach to care for Aboriginal and/or Torres Strait Islander Health Workers. For more information visit <http://pepaeducation.com/support-and-education/palliative-approach-to-care-for-aboriginal-and-torres-strait-islander-health-workers/>.

7.1.1 Return to Country

Many Aboriginal and Torres Strait Islander people have a strong connection to traditional lands, and the need to 'return to Country' before the end of life or at the end of life can be both culturally and spiritually significant. It is essential that this wish be honoured and facilitated by health services.

Where the patient prefers to be cared for at home, health services should act to support the family and carers in providing appropriate palliative care. This may involve working with health services outside of normal geographical or jurisdictional boundaries and arranging:

- patient transfer/transport
- transfer of medical equipment
- liaison with other health services to ensure continuity of care
- training of carers in personal care of the patient and administering medication
- respite care
- funding to assist with any of the above arrangements.

The palliative care planning should identify any relevant customs a patient and their family may practise, and the multidisciplinary palliative care team should work with the patient, their family and carers to develop strategies to support these requests.

7.1.2 Pain management

Aboriginal and Torres Strait Islander people have identified managing pain relief as one of the most challenging aspects of end-of-life care (McGrath 2006). Effective pain management requires an appreciation and respect of cultural perspectives regarding pain.

Aboriginal and Torres Strait Islander people experiencing pain may:

- be quiet and reserved
- practice centering, which involves being still and entering a deep spiritual and psychological focus to shut the pain out
- be less inclined to report pain, even when specifically asked (McGrath 2006).

A lack of request for pain relief should not be interpreted as a lack of need.

When assessing pain and pain management for Aboriginal and Torres Strait Islander patients, health professionals should be aware of the following:

- There are significant cultural practices regarding which family members (which may include Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners) can assist with providing pain relief
- Aboriginal and Torres Strait Islander people may be hesitant to administer pain relief to other people
- Patients may not report pain.
- Men's and Women's Business may prevent some patients from discussing certain aspects of pain or pain management.
- Some patients may be uncomfortable with pain medication administered via injection or through an intravenous drip.
- Concerns about the side effects of pain relief (particularly sleepiness or constipation) or addiction may also prevent patients from requesting or accepting pain relief.
- There may be fears that pain-relief medicines may accelerate the passing of the patient, or be considered a form of euthanasia (McGrath 2006).

Effective strategies to manage pain for Aboriginal and Torres Strait Islander people include:

- being proactive about offering patients pain relief
- offering the option for patients to discuss their pain and pain management with a health professional of the same gender, wherever possible
- using oral pain relief options if preferred by the patient, where appropriate
- developing and/or using a culturally appropriate pain tool
- fully explaining the options, usage and side effects of pain relief in plain language
- providing information about services that can assist with pain management or further questions, particularly when pain management is happening outside of the hospital environment.

When end-of-life pain management occurs outside of the hospital environment and is predominantly or completely provided by family members or other non-health professional carers, it is essential that a home care pain management plan is developed in consultation with the people who will be administering the pain relief. The pain management plan should clearly establish:

- the type of pain relief to be used and the dosage
- clear instructions regarding the route of administration and side effects
- how further prescriptions or pain relief can be accessed, if needed
- whether there are any potential barriers to administering the pain relief at present, or as end-of-life approaches, and strategies to address these
- who to contact if there are any questions or concerns.

The pain management plan should be discussed verbally with the patient and their family and carers. Supply written copies to take home.

Further information

- Refer to the Poche Health Best evidence summary for pain management at <http://pochehealth. edu.au/best-evidence-summary-for-pain-management/>.

7.1.3 Practices around death and dying

The practices observed around death and dying vary significantly between individuals and Aboriginal and Torres Strait Islander communities. Health services should discuss cultural preferences with all patients and are encouraged to consult with their local Aboriginal and Torres Strait Islander personnel and communities for further guidance on how to best provide care and support to the patient, their family and carers during this period.

Family members may require financial assistance with funeral costs, expenses associated with returning the body to Country for burial, or travel for relatives. Health services should make themselves familiar with what assistance is available in the local area and connect families and Elders with support services and appropriate agencies, wherever possible.

There are a number of further general considerations that health services and professionals should be aware of. These differ across communities, and local knowledge and context should be considered.

Many Aboriginal and Torres Strait Islander people find it inappropriate to say or write the name of a person who has recently died, owing to spiritual beliefs. Use of images or voice recordings of the deceased person may also be considered offensive. Health professionals should consult with local Aboriginal and/or Torres Strait Islander Health Workers, Health Practitioners or Hospital Liaison Officers to determine what word should be used in place of the patient's name after their passing and/or follow cues from the family and carers regarding the appropriate terms to use.

The next of kin may not be the appropriate person to contact following the death of a patient. The correct contact should be identified early in the palliative care period to ensure the correct protocols can be followed at the time of the patient's passing.

It may also be inappropriate for a non-Indigenous health professional to relay the news that an Aboriginal and Torres Strait Islander patient has died. Health professionals should consult with local Aboriginal and/or Torres Strait Islander Health Workers, Health Practitioners or Hospital Liaison Officers for guidance throughout this process.

If health professionals have established a relationship with the patient and their family, it is considered respectful to attend the funeral.
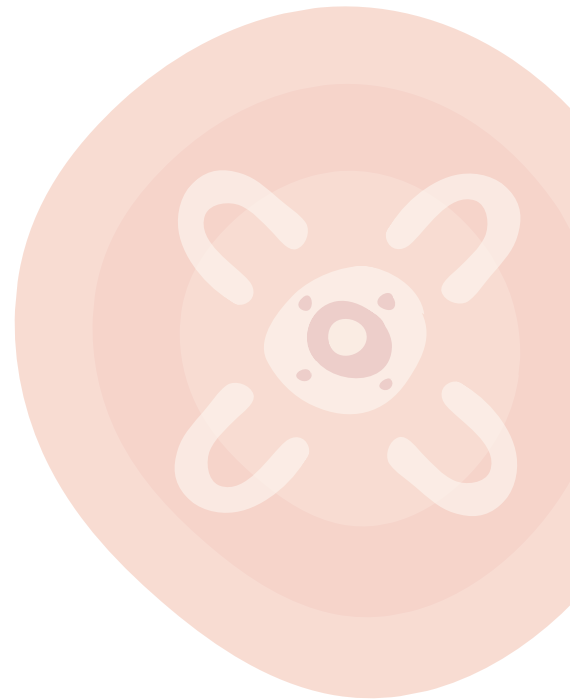
Health services should appreciate that some Aboriginal and Torres Strait Islander health professionals may have cultural obligations that will conflict with the professional role and may require leave for enacting cultural responsibilities following the death of a patient and/or family member.

7.2   Research and clinical trials

All patients should be offered the opportunity to participate in a clinical trial or clinical research if appropriate. Refer to section 3.4 for more detailed information.

Further information

- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <http://www.australiancancertrials.gov.au/>.

- See the National Health and Medical Research Council's Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research at <https://www.nhmrc.gov.au/guidelines-publications/e52> and Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics at <https://www.nhmrc.gov.au/guidelines-publications/e65>.

- The National Health and Medical Research Council's National statement on ethical conduct in human research is available at <https://www.nhmrc.gov.au/guidelines-publications/e72>.

7.3 Support and communication

7.3.1 Supportive care

An individualised clinical assessment is required to assess and meet the needs of people with cancer, their families and carers; referral should be as required. Refer to section 2.4.1 for detailed information about providing supportive care to Aboriginal and Torres Strait Islander people affected by cancer.

Specific needs associated with end-of-life care may include the following.

Physical needs

- Decline in mobility or functional status affecting the patient's discharge destination will need to be considered.

Cognitive dysfunction and personality and behavioural changes

- There may be severe behavioural changes or dementia, and specific management by a neuro-psychologist/psychiatrist is often required during this stage of disease progression.

Psychological needs

- Patients, carers, Elders and families may need strategies to deal with emotional and psychological distress from anticipatory grief, fear of death/dying, anxiety/depression, interpersonal problems and anticipatory bereavement support.
- Patients who experience existential distress may benefit from supportive psychotherapy.

Social/practical needs

- Support may be required for the practical, financial and emotional impacts on carers, Elders and family members resulting from the increased care needs of the patient.
- Specific support should be provided for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs.
- Potential isolation from normal support networks, particularly for rural and remote patients who have been staying away from home for treatment, may be an issue. Many Aboriginal and Torres Strait Islander people with cancer speak of being treated or feeling like an outcast in their community because of the stigma associated with cancer. Social isolation may require referral to counselling services.

Information needs

- Communication about the death and dying process (using culturally appropriate terms) and what to expect is important.
- All members of the care team should be notified when the patient has died.
- Culturally appropriate information and resources should be provided including information for patients, Elders and families about arranging a funeral.

Spiritual needs

- Bereavement support should be provided for family, Elders and friends.
- Patients with cancer and their families and Elders should have access to spiritual support appropriate to their needs throughout the cancer journey.

Further information

- Learn about the SCNAT-IP at <www.scnatip.org>.
- Learn about the NCCN distress thermometer at <http://edcan.org.au/edcan-learning-resources/supporting-resources/supportive-care/screening>.

7.3.2 Communication with the patient, carer and family

The lead clinician should:

- be open to and encourage discussion about the expected disease course while considering the patient's personal and cultural beliefs and expectations
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements
- provide the patient and carer with the contact details of a palliative care service or initiate telehealth or a conference call with the local palliative care team while the patient is present (an introduction may facilitate discussions on, or referral to, palliative care)
- ensure the family and carer(s) understand and have written or other accessible-format information about the supportive care and pain management plans, and provide a culturally safe and responsive opportunity to address any questions or concerns with providing care.

7.3.3 Communication with the general practitioner

The lead clinician should discuss end-of-life care planning (including pain management) and transitioning planning with the patient's general or primary practitioner to ensure the patient's needs and goals are addressed in the appropriate environment. The patient's general or primary practitioner should be kept fully informed and involved in major developments in the patient's illness trajectory.

Tumour-specific information

For specific information about the most frequently diagnosed cancers (incidence) in Aboriginal and Torres Strait Islander people, please refer to the relevant tumour-specific OCPs:

Breast | Colorectal (bowel and rectal) | Head and neck | Hepatocellular (liver) | Lung | Prostate
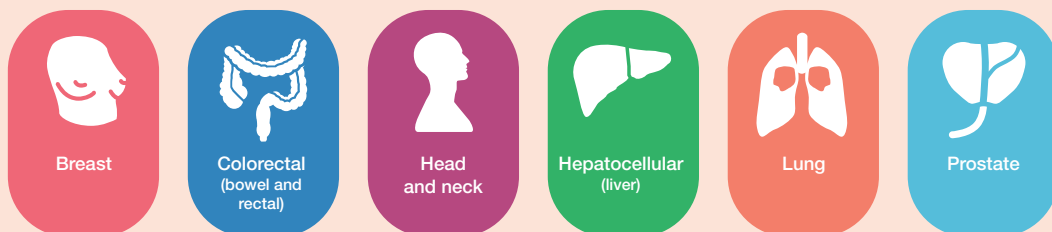
Appendix: Quick reference guides

The quick reference guides are two-page summaries of the key information from the tumour-specific clinical OCPs.

The quick reference guides on the following pages are for all populations groups. They are presented here because they are the most frequently diagnosed cancers (incidence) in Aboriginal and Torres Strait Islander populations.

| Breast | Colorectal (bowel and rectal) | Head and neck | Hepatocellular (liver) | Lung | Prostate |
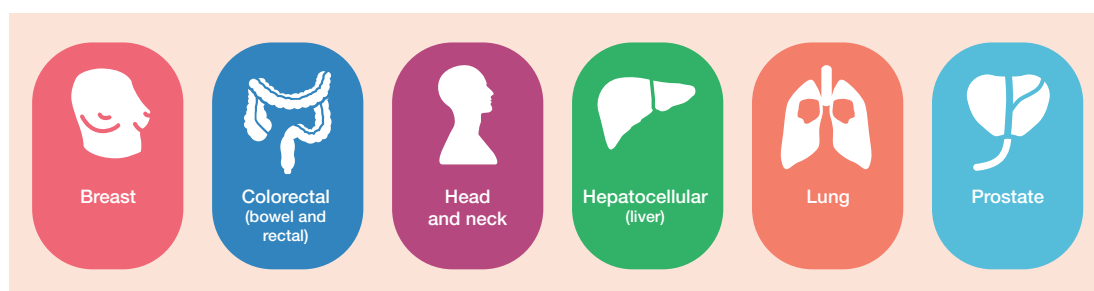
To view the clinical versions of the tumour-specific OCPs, visit <www.cancer.org.au/OCP>.

Optimal care pathway for women with breast cancer

Quick reference guide

Please note that not all women will follow every step of this pathway:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1 — Prevention and early detection

Risk factors: Age, sex, family history, obesity and moderate/heavy alcohol intake are important risk factors. All women should have their individual breast cancer risk assessed.

Women at moderate or high risk should be referred to a family cancer clinic to have their risk further clarified and for possible genetic testing.

Risk reduction: For women at moderate or high risk of breast cancer, anti-hormonal risk-reducing medication should be considered. Women at very high risk should consider risk-reducing surgery. The surgeon should provide clear information about the objective of the procedure.

Screening: Federally funded mammographic screening is available to asymptomatic women from the age of 40 through the BreastScreen Australia Program. Women aged 50-74 years should consider undergoing a two - yearly screening mammogram. Over-diagnosis needs to be considered, and women invited to screening must be informed of the potential disadvantages as well as the benefits of mammographic screening.

Increased or high risk - refer to the breast optimal care pathway for screening recommendations.

Step 2 — Presentation, initial investigations and referral

Signs and symptoms:

The following should be investigated:

- a new lump or lumpiness
- a change in the size or shape of a breast
- a change to a nipple
- nipple discharge that occurs without squeezing
- a change in the skin of a breast
- axillary masses
- an unusual breast pain that does not go away.

Assessments by a general practitioner (GP)

GP should refer all women with a suspicious lesion to a breast assessment clinic.

Examinations/investigations should include a triple test of three diagnostic components:

- medical history and clinical breast examination
- imaging – mammography and/or ultrasound
- non-excision biopsy – fine needle aspiration (FNA) cytology and/or a core biopsy.

These tests should be done within two weeks.

Referral: A positive result on any component of the triple test warrants referral for specialist surgical assessment and/or further investigation. Optimally, the specialist appointment should be within two weeks of a suspected diagnosis.

Communication – lead clinician to:

- provide the woman with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for an appointment
- support the woman while waiting for the specialist appointment.

Step 3 — Diagnosis, staging and treatment planning

Diagnostic work-up for women with breast cancer: Family history and a medical examination, then consider following sequence of investigations:

- breast imaging tests
- ultrasound of the axilla +/- FNA nodes
- breast core biopsy if not already undertaken
- establishment of breast cancer receptor profile
- assessment for a breast cancer predisposition gene and considered for genetic counselling.

Staging: Appropriate for locally advanced or confirmed nodal disease and for any women with clinical symptoms or clinical suspicion of metastatic disease.

Treatment planning: All newly diagnosed women should be discussed by a multidisciplinary team so that a treatment plan can be recommended.

Special considerations that need to be addressed at this stage include pregnancy, fertility and prevention of chemotherapy-induced menopause.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the woman/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

1 Lead clinician – the clinician who is responsible for managing patient care.
The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

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Step 4

Treatment:

Establish intent of treatment:

- curative
- anti-cancer therapy to improve quality of life and/ or longevity without expectation of cure
- symptom palliation.

Treatment options:

Surgery: Surgery for early breast cancer involves either breast-conserving surgery or mastectomy performed with or without immediate breast reconstruction surgery. Women should be fully informed of their options and offered the option of immediate or delayed reconstructive surgery if appropriate.

Chemotherapy and other systemic therapy: Chemotherapy or drug therapy may be appropriate as neoadjuvant or adjuvant treatment.

Radiation therapy: In most cases, radiation therapy is recommended for women with early breast cancer after breast-conserving surgery and in selected women after mastectomy.

For detailed information see <http://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/clinical-practice-guidelines-management-early-breast-cancer-2nd-ed>.

Communication – lead clinician to:

- discuss treatment options with the woman/carer including the intent of treatment and expected outcomes
- discuss the treatment plan with the woman's GP.

Step 5

Care after initial treatment and recovery

Cancer survivors should be provided with the following to guide care after initial treatment.

Treatment summary (provide a copy to the woman/carer and her GP) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

Follow-up care plan (provide a copy to the woman/carer and her GP) outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the woman/carer
- inform the woman/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the woman's GP.

Step 6

Managing recurrent, residual and metastatic disease

Detection: Some cases of recurrent disease will be detected by routine follow-up in a woman who is asymptomatic. Some cases of metastatic disease will be detected at the same time as presentation with the initial primary breast cancer ('de novo metastatic disease').

Treatment: Where possible, refer the woman to the original multidisciplinary team. Treatment will depend on the location, the extent of recurrence, previous management and the woman's preferences.

Palliative care: Early referral can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

For detailed information see <http://annonc.oxfordjournals.org/content/early/2014/09/17/annonc.mdu385.full.pdf+html>.

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the woman/carer
- initiate a discussion regarding advance care planning if appropriate.

Step 7

End-of-life care

Palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the woman/carer
- establish transition plans to ensure the woman's needs and goals are addressed in the appropriate environment.

Visit www.cancerpathways.org.au for consumer friendly guides. Visit www.cancer.org.au/OCP for the full clinical version and instructions on how to import these guides into your GP software.

Optimal care pathway for people with colorectal cancer

Quick reference guide

Please note that not all patients will follow every step of this pathway:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1
Prevention and early detection

Prevention:
- eating a healthy diet, including plenty of vegetables, fruit and whole grains while minimising intake of red meat and processed meat
- maintaining a healthy body weight
- exercising regularly
- avoiding or limiting alcohol intake
- not smoking.

Early detection:
- Average risk
- No personal history of colorectal cancer, adenoma or chronic inflammatory bowel disease, or
- No more than one close relative diagnosed at age 55 or older.

Screening recommendations:
- If over 50 years, screen every two years using a faecal occult blood test (FOBT)
- Participation in the National Bowel Cancer Screening Program recommended if eligible.

Increased or high risk – refer to the colorectal optimal care pathway for screening recommendations.

Step 2
Presentation, initial investigations and referral

The following signs and symptoms should be investigated:
- positive FOBT
- passage of blood with or without mucus in the faeces
- unexplained iron deficiency anaemia
- change in bowel habit (loose stools or constipation)
- undiagnosed abdominal pain
- unexplained rectal or abdominal mass
- unexplained weight loss
- the presence of multiple signs and symptoms.

Positive screening test: All patients with a positive FOBT should be referred for a colonoscopy within four weeks.

Initial investigations include:
- physical examination
- digital rectal examination
- blood tests including iron studies.

Test results should be provided to the patient within one week.

Referral: If symptoms suggest cancer, the patient should be referred for a colonoscopy within four weeks.

Communication – lead clinician to:[1]
- explain to the patient/carer who they are being referred to and why
- support the patient/carer while waiting for specialist appointments.

Step 3
Diagnosis, staging and treatment planning

Diagnosis and staging:
- For colon cancer
  - Computed tomography (CT) scan of the chest, abdomen and pelvis
  - Whole-body fluoro-deoxyglucose positron emission tomography (FDG PET) (if suspected limited metastatic disease)
- For rectal cancer:
  - CT scan of chest, abdomen and pelvis
  - Local staging with magnetic resonance imaging (MRI) and/or endoscopic rectal ultrasound

Treatment planning: All newly diagnosed patients should be discussed by a multidisciplinary team. Patients with rectal cancer should be discussed prior to surgery.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:
- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

1 Lead clinician – the clinician who is responsible for managing patient care.
  The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Step 4

Treatment:

Establish intent of treatment:

- curative
- anti-cancer therapy to improve quality of life and/ or longevity without expectation of cure
- symptom palliation.

Surgery:

- Surgery is frequently recommended for patients with colorectal cancer.
- Surgeons should have adequate qualifications and expertise, especially those undertaking rectal surgery.

Radiation therapy may benefit people with:

- high-risk rectal cancer for whom adjuvant preoperative (or less commonly post-operative) radiation therapy is recommended
- symptomatic non-resectable locally advanced cancer who may benefit from radiation with palliative intent.

Chemotherapy or drug therapy may benefit people with:

- a high risk of relapse
- locally advanced rectal cancer, treated with neoadjuvant chemo-radiation
- non-resectable locally advanced or metastatic disease.

Palliative care: Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:

- discuss treatment options with the patient/carer including the intent of treatment as well as risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

For detailed information see http://www.nhmrc.gov.au/guidelines/publications/cp106

Step 5

Care after initial treatment and recovery

Cancer survivors should be provided with the following to guide care after initial treatment.

Treatment summary (provided to the patient, carer and general practitioner) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided.

Follow-up care plan (provide a copy to patient/ carer and general practitioner) outlining:

- medical follow-up required (tests, ongoing surveillance)

- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the patient/carer
- inform the patient/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the patient's general practitioner.

Step 6

Managing recurrent, residual and metastatic disease

Detection: Most residual or recurrent disease will be detected via routine follow-up or by the patient presenting with symptoms.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the location and extent of disease, previous management and patient preferences.

Palliative care: Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the patient/carer.

Step 7

End-of-life care

Palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the patient
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

Visit www.cancerpathways.org.au for consumer friendly guides. Visit www.cancer.org.au/OCP for the full clinical version and instructions on how to import these guides into your GP software.

Optimal care pathway for people with head and neck cancers

Quick reference guide

Please note that not all patients will follow every step of this pathway:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1
Prevention and early detection

Prevention: The uptake of human papillomavirus (HPV) vaccination by Australian boys and girls 12–13 years of age should be encouraged. Strategies to curb alcohol intake and smoking and reduce to ultraviolet (UV) exposure will reduce future head and neck cancer burden.

Risk factors: Users of both tobacco and alcohol have a 50-fold (or greater) increased risk of developing head and neck cancer. Other risk factors include:
- age (over 40 years)
- sex (male)
- pre-existing oral lesions

- HPV exposure
- Epstein-Barr virus infection (for nasopharyngeal cancer)
- immunosuppressed patients
- ionising radiation exposure
- UV skin exposure (for skin cancer)
- inherited conditions.

Step 2
Presentation, initial investigations and referral

Signs and symptoms: The following symptoms should be investigated if they persist for more than three weeks, especially if there is more than one symptom:
- hoarseness or altered speech
- difficulty swallowing
- persistent sore throat (particularly with earache)
- unexplained neck or parotid lump
- mouth ulcer or mass
- leukoplakia (white or red patches) of oral mucosa
- unexplained tooth mobility and/or non-healing dental extraction site
- spitting or coughing up blood
- unilateral blockage of the nose or ear.

General/primary practitioner investigations: Ultrasound-guided fine needle aspiration cytology (USgFNAC) of a node if there is suspicion of malignancy. Non-fine-needle aspiration (FNA) biopsies should not be carried out in a non-specialist setting.

Referral: All patients with a suspected head and neck cancer should be referred to a head and neck specialist with expertise in these cancers and who is affiliated with a multidisciplinary team within two weeks of identification by a general practitioner or dentist.

Communication – lead clinician to:[1]
- offer smokers advice about smoking cessation
- explain to the patient/carer who they are being referred to and why
- support the patient and carer while waiting for specialist appointments.

Step 3
Diagnosis, staging and treatment planning

Diagnosis and staging: The following investigations should be undertaken:
- complete head and neck examination, including endoscopy
- scans to evaluate the primary site, preferably prior to biopsy to avoid the effect of upstaging from the oedema
- FNA for assessment of patients with neck or thyroid lumps inaccessible to biopsy
- biopsy (arranged by a specialist).

Staging:
- Computerised tomography (CT) and magnetic resonance imaging (MRI) of both the primary site and neck lymph nodes.
- MRI is for assessing tumours of the nasopharynx and paranasal sinuses and for cancers with skull base invasion, soft tissue intracranial extension and perineural tumour spread.
- Positron emission tomography (PET) CT is an important staging tool in locally advanced head and neck cancers.

Treatment planning: All newly diagnosed patients should be discussed in a multidisciplinary team meeting so that a treatment plan can be recommended.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:
- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

1 Lead clinician – the clinician who is responsible for managing patient care.
  The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

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Step 4

Treatment:

Establish intent of treatment:
- curative
- anti-cancer therapy to improve quality of life and/ or longevity without expectation of cure
- symptom palliation.

Having access to specialist nursing and allied health disciplines (in particular specialist speech pathology and dietetics) is important for managing the physical, psychological and social/ practical needs that may arise with head and neck cancer treatment.

Treatment options:

Surgery: This is a treatment option for the majority of head and neck cancer patients.

Radiation therapy: This can be delivered as primary treatment for organ conservation, usually concurrently with chemotherapy. It is also given following surgery (postoperatively) for patients at high risk of locoregional recurrence.

Chemotherapy or drug therapy: Concurrent or adjuvant chemoradiation has now become the standard of care in locally advanced head and neck squamous cell carcinoma. There are selected clinical scenarios where neoadjuvant chemotherapy (prior to radiation therapy) is also appropriate.

Palliative care: Early referral can improve quality of life. Referral should be based on need, not prognosis.

Communication – lead clinician to:
- discuss treatment options with the patient/carer including the intent of treatment as well as the risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

For detailed information see <http://oralcancerfoundation.org/treatment/pdf/head-and-neck.pdf>.

Step 5

Care after initial treatment and recovery

Treatment summary (provide a copy to the patient/carer and general practitioner) outlining:
- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

Follow-up care plan (provide a copy to the patient/carer and general practitioner) outlining:
- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:
- explain the treatment summary and follow-up care plan to the patient/carer
- inform the patient/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the patient's general practitioner.

Step 6

Managing recurrent, residual and metastatic disease

Detection: Most cases of recurrent head and neck cancers are identified through routine follow-up or when the patient presents with symptoms.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the location and extent of disease, performance status, previous management and the patient's preferences.

Palliative care: Early referral can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:
- explain the treatment intent, likely outcomes and side effects to the patient/carer.

Step 7

End-of-life care

Palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Communication – lead clinician to:
- be open about the prognosis and discuss palliative care options with the patient/carer
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

Visit www.cancerpathways.org.au for consumer friendly guides. Visit www.cancer.org.au/OCP for the full clinical version and instructions on how to import these guides into your GP software.

Optimal cancer care pathway for people with hepatocellular carcinoma

Quick reference guide

Please note that not all patients will follow every step of this pathway:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1
Prevention and early detection

Prevention: Immunisation for hepatitis B (HBV), monitoring of patients with HBV and hepatitis C (HCV) and use of antiviral drugs can reduce the risk of infection developing into cancer.

Strategies to curb alcohol intake and reduce obesity (and hence type 2 diabetes and non-alcoholic fatty liver disease) will also reduce future hepatocellular carcinoma (HCC) burden.

Risk factors include:

- chronic HCV infection
- HBV infection
- a family history of HCC
- cirrhosis of the liver of any cause.

Other risk factors: male gender, older age, viral co-infection, chronic alcohol consumption, obesity, non-alcoholic fatty liver disease, type 2 diabetes, iron overload, aflatoxin exposure and tobacco smoking.

Early detection: Australia does not have a population screening program for HCV, HBV or HCC. Surveillance for HCC should be based on six-monthly abdominal ultrasound in high-risk groups.

Step 2
Presentation, initial investigations and referral

Signs and symptoms: The following signs and symptoms should be investigated:

- right upper quadrant abdominal pain or discomfort
- a hard lump on the right side of the abdomen
- worsening liver failure (jaundice, ascites, portal hypertension)
- constitutional symptoms
- the presence of multiple signs and symptoms.

Initial investigations include:

- ultrasound assessment of liver and renal function
- assessment of tumour markers (alpha-fetoprotein (AFP))
- full blood examination
- HBV and HCV serology (HBsAg, anti-HCV antibody).

Tests should be conducted within two to three days of symptom discovery.

Referral: Refer all patients with suspected or proven HCC to a specialist linked with a multidisciplinary team within one week. The multidisciplinary team should have a rapid access program/contact person.

Communication – lead clinician to:[1]

- explain to the patient/carer who they are being referred to and why
- support the patient and carer while waiting for specialist appointments.

Step 3
Diagnosis, staging and treatment planning

Diagnosis: The following sequence of investigations is suggested:

- four-phase contrast-enhanced computed tomography (CT) scan
- magnetic resonance imaging (MRI) with contrast in patients who cannot tolerate CT contrast or where diagnostic uncertainty remains
- contrast-enhanced ultrasound, in select cases.

If diagnostic uncertainty still remains, conduct:

- positron emission tomography (PET)
- a liver biopsy (particularly if no surgery is planned).

Staging: Staging parameters include imaging (metastases and vascular invasion), Eastern Cooperative Oncology Group (ECOG) status and Child–Pugh score.

Treatment planning: All patients with suspected or proven HCC should be discussed by a multidisciplinary team before treatment begins.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

1 Lead clinician – the clinician who is responsible for managing patient care.
The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

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Step 4

Treatment:

Establish intent of treatment:
- curative
- anti-cancer therapy to improve quality of life and/ or longevity without expectation of cure
- symptom palliation.

Treatment of localised HCC

Local ablative therapies are the most common treatment for HCC. They may benefit patients:

- with unresectable disease (due to the size or location of the tumour)
- with a small tumour or tumours (lesions 3 cm or smaller)
- awaiting liver transplant
- with small recurrent tumours.

Surgery – resection or transplant: Resection may benefit patients with compensated liver disease and a resectable tumour. Liver transplant may benefit patients with the presence of cirrhosis, including those with decompensation.

Regional therapies: Transarterial chemoembolisation (TACE), selective internal radiation therapy (SIRT) or stereotactic therapy may be appropriate.

Treating advanced HCC

The standard treatment for patients with advanced HCC is either: sorafenib; surveillance and management of the underlying disease; or a combination of surgery and surveillance. Palliation of symptoms may include TACE, surgery, radiation and other therapies.

Palliative care: Early referral can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:

discuss treatment options with the patient/carer including the intent of treatment as well as risks and benefits

discuss advance care planning with the patient/carer where appropriate

- discuss the treatment plan with the patient's general practitioner.

For detailed information see www.aasld.org/practiceguidelines/pages/default.aspx

Step 5

Care after initial treatment and recovery

Management of the underlying liver disease must be carefully managed to help prevent recurrence.

Cancer survivors should be provided with the following to guide care after initial treatment.

Treatment summary (provide a copy to the patient/carer and general practitioner) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

Follow-up care plan (provide a copy to the patient/carer and general practitioner) outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:

explain the treatment summary and follow-up care plan to the patient/carer

inform the patient/carer about secondary prevention and healthy living

- discuss the follow-up care plan with the general practitioner.

Step 6

Managing recurrent, residual and metastatic disease

Detection: Most residual or recurrent disease will be detected via routine follow-up or when the patient presents with symptoms.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the location and extent of disease, previous management and the patient's preferences.

Palliative care: Early referral can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the patient/carer.

Step 7

End-of-life care

Palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Communication – lead clinician to:

be open about the prognosis and discuss palliative care options with the patient/carer

- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

Visit www.cancerpathways.org.au for consumer friendly guides. Visit www.cancer.org.au/OCP for the full clinical version and instructions on how to import these guides into your GP software.

Optimal care pathway for people with lung cancer

Please note that not all patients will follow every step of this pathway:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1
Prevention and early detection

Prevention:

- All current smokers should be offered advice to quit smoking. **Effective strategies include:**
  - advice on quitting smoking and structured interventions by health professionals
  - individual or group counselling programs such as Quit (refer to www.quit.org.au)
  - nicotine replacement therapy and other pharmacological agents.

Risk factors:

- Lifestyle factor:
  - tobacco smoking
- Environmental factors:
  - passive smoking
  - radon exposure
  - occupational exposure (such as asbestos and diesel exhaust)
  - air pollution

- Personal factors:
  - age
  - family history of lung cancer
  - chronic lung disease

Early detection: No form of population screening has been shown to improve lung cancer outcomes.

Step 2
Presentation, initial investigations and referral

Signs and symptoms:

The following unexplained or persistent signs or symptoms lasting more than three weeks (or less than three weeks in people with known risk factors) require urgent referral for a chest x-ray: unexplained haemoptysis **or** persistent new/changed cough, chest/shoulder pain, breathlessness, hoarseness, weight loss, finger clubbing, unresolved chest infection, abnormal chest signs, features suggestive of metastasis from a lung cancer, and signs of pleural effusion.

Persistent haemoptysis and/or signs of superior vena cava obstruction require urgent referral to a specialist linked to a multidisciplinary team. Massive haemoptysis and/or signs of stridor require immediate referral to an emergency department.

General/primary practitioner investigations: Chest x-ray; if cancer is suspected refer immediately. Contrast spiral computed tomography (CT) of the chest and upper abdomen if the chest x-ray is clear and symptoms persist. Immediate referral if the CT is abnormal. Test results should be provided to the patient within one week. The first specialist appointment should take place within two weeks of referral.

Referral: Refer all patients with suspected or proven lung cancer to a specialist linked with a multidisciplinary team.

Communication – lead clinician to:[1]

- explain to the patient/carer who they are being referred to and why
- support the patient and carer while waiting for specialist appointments.

Step 3
Diagnosis, staging and treatment planning

Diagnosis: May be obtained from bronchoscopy including endobronchial ultrasound (EBUS), CT-guided biopsy, excisional biopsy or biopsy of metastasis, or sputum cytology (rarely).

Staging: Radiological staging based on CT scan of the chest and upper abdomen and one of the brain. Other tests to confirm the cancer stage may include bronchoscopy, thoracoscopy, thoracotomy, mediastinoscopy, endobronchial/oesophageal ultrasound (EBUS/EUS) and nuclear medicine tests including bone and positron emission tomography (PET) scans, with biopsies to establish pathology.

Treatment planning: All patients with suspected or proven lung cancer should be discussed by a multidisciplinary team before treatment begins.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

1 Lead clinician – the clinician who is responsible for managing patient care.
The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

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Step 4

Treatment:

Establish intent of treatment:

- curative
- anti-cancer therapy to improve quality of life and/ or longevity without expectation of cure
- symptom palliation.

Surgery:

- Surgery will benefit people with early stage non-small-cell lung cancer (NSCLC) who are fit and those requiring surgical diagnosis or palliation.

Radiation therapy may benefit people with:

- NSCLC who are not suitable for surgery or have locally advanced disease and are being treated with combined modality therapy
- small-cell lung cancer (SCLC) having combined modality treatment or those who would benefit from prophylactic cranial irradiation.

All patients may benefit from radiation therapy for palliative intent.

Chemotherapy or drug therapy may benefit people with:

- advanced disease and good performance status
- NSCLC who are having neoadjuvant or adjuvant therapy in conjunction with completed resection of locoregional disease
- inoperable localised NSCLC who are considered suitable for combined modality definitive chemoradiation.

Palliative care: Early referral can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:

- discuss treatment options with the patient/carer including intent of treatment as well as risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

For detailed information see http://www.wiki.cancer.org.au/australia/Guidelines:Lung_cancer.

Step 5

Care after initial treatment and recovery

Cancer survivors should be provided with the following to guide care after initial treatment.

Treatment summary (provide a copy to the patient/carer and general practitioner) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided.

Follow-up care plan (provide a copy to patient/ carer and general practitioner) outlining:

- medical follow-up required (tests, ongoing surveillance)

- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the patient/carer
- inform the patient/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the general practitioner.

Step 6

Managing recurrent, residual and metastatic disease

Detection: Most residual or recurrent disease will be detected via routine follow-up or when the patient presents with symptoms.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the location and extent of disease, previous management and the patient's preferences.

Palliative care: Early referral can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the patient/carer.

Step 7

End-of-life care

Palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the patient/carer
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

Visit www.cancerpathways.org.au for consumer friendly guides. Visit www.cancer.org.au/OCP for the full clinical version and instructions on how to import these guides into your GP software.

Optimal care pathway for men with prostate cancer

Quick reference guide

Please note that not all patients will follow every step of this pathway:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1
Prevention and early detection

Prevention: The causes of prostate cancer are not fully understood and there is currently no clear prevention strategy.

Early detection

Risk factors include:

- increasing age
- family history of prostate cancer
- certain dietary factors

- race (men of Caucasian background are more at risk than Asian men).

Case finding: Men at higher risk (based on their family history) should be counselled regarding their risk. PSA testing should be considered.

Men in good health may consider tests for early detection after discussing the risks and benefits with their primary care provider.

Step 2
Presentation, initial investigations and referral

Signs and symptoms

- The majority of men presenting with prostate cancer have no symptoms.
- Syptoms of locally advanced disease may include irritation on urination, obstructive urinary symptoms and/or blood in the urine.

Initial investigations include:

- PSA level
- measurement of free-to-total PSA ratio.

The significance of rising PSA (i.e. free-to-total PSA ratio), even within the age-adjusted normal range, should be recognised, as well as a PSA that is at the high end of the normal range in younger men.

Assessments by the general practitioner should be completed within one week.

Referral: The patient should be referred to a urologist within six to 12 weeks (without symptoms) and earlier if symptomatic.

Communication – lead clinician[1] to:

- explain to the patient/carer who they are being referred to and why
- support the patient/carer while waiting for specialist appointments.

Step 3
Diagnosis, staging and treatment planning

Implications of both a positive and negative biopsy result should be discussed with the patient before biopsy. A prostate biopsy should not be offered on the basis of serum PSA level alone.

Diagnosis and staging:

- DRE (prior to biopsy)
- prostate biopsy
- with or without prostate magnetic resonance imaging (MRI).

The use of staging investigations in men with clinically localised disease should be based on their risk of metastatic spread (Gleason score, clinical stage, PSA), and provisional treatment intent. Tests may include:

- DRE assessment
- isotope bone scans
- computed tomography (CT) scan and/or prostate MRI
- Interval reimaging (to determine the appropriate timing of androgen deprivation therapy (ADT).

Treatment planning: All newly diagnosed patients should be discussed by a multidisciplinary team before beginning treatment.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

Offer advice on how to access support from prostate cancer peer support groups and groups for carers; visit www.prostate.org.au for local area listings.

1 Lead clinician – the clinician who is responsible for managing patient care.
  The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Step 4

Treatment:

Establish intent of treatment:
- curative
- anti-cancer therapy to improve quality of life and/ or longevity without expectation of cure
- symptom palliation.

If curative treatment is considered, men should be offered an opportunity for a second opinion in order to have a balanced view about the available treatment options.

Treatment of localised or locally advanced prostate cancer:

- **Watchful waiting:** some patients (for example, those with other health issues who are not expected to live more than 7 years) should be monitored and symptoms treated if they arise.
- **Active surveillance:** some men with low-risk prostate cancer should be regularly monitored for signs of disease progression so curative treatment can be initiated if necessary.
- **Surgery (radical prostatectomy):** may benefit some men with at least a 10-year life expectancy.

- **Radiation therapy by external beam radiotherapy (EBRT) or brachytherapy +/– ADT:** may benefit patients with at least a 10-year life expectancy.

Treatment of advanced prostate cancer:

- **ADT** is the standard treatment. The timing of starting ADT is often related to balancing the risk of side effects against the unwanted effects of the disease.
- For patients with metastatic disease, chemotherapy, second-generation anti-androgens, bisphosphonates and RANK ligand inhibitors may be of benefit.

Palliative care: Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:
- discuss treatment options with the patient/carer including the intent of treatment as well as the risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

http://wiki.cancer.org.au/australia/Guidelines:Prostate_cancer/Management/Locally_advanced_and_metastatic.

Step 5

Care after initial treatment and recovery

Cancer survivors should be provided with the following to guide care after initial treatment.

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- tumour characteristics
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- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:
- explain the treatment summary and follow-up care plan to the patient/carer
- inform the patient/carer about late effects, secondary prevention and healthy living
- discuss the follow-up care plan with the patient's general practitioner.

Step 6

Managing recurrent, residual and metastatic disease

Detection: Most residual or recurrent disease will be detected by a rising PSA in asymptomatic men.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the location and extent of disease, previous management and patient preferences.

Palliative care: Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:
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Step 7

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Palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Communication – lead clinician to:
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- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

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Glossary

Aboriginal and/or Torres Strait Islander Health Practitioner – a person who identifies as being of Aboriginal and/or Torres Strait Islander heritage, meets the qualification requirements, and is registered with the Australian Health Practitioner Regulation Agency.

Aboriginal and/or Torres Strait Islander Health Worker – a person who identifies as being of Aboriginal and/or Torres Strait Islander heritage, works in primary healthcare, and holds the required specified Aboriginal and Torres Strait Islander primary healthcare qualification.

Aboriginal and/or Torres Strait Islander Hospital Liaison Officer – a person who identifies as being of Aboriginal and/or Torres Strait Islander heritage and works in a hospital to provide a range of support for staff, patients and their families.

Aboriginal Community Controlled Health Service – a primary health care service that publicly recognises itself as an Aboriginal Community Controlled Health Service, and delivers holistic, comprehensive, and culturally appropriate health care to the community.

Aboriginal Medical Service – a health service that publicly recognises itself as an Aboriginal Medical Service, and delivers services to a predominantly Aboriginal and Torres Strait Islander population. An AMS is not necessarily community controlled.

Advance care planning – a process of discussing future medical treatment and care based on an individual's preferences, goals, beliefs and values, which can guide future decisions should the person become unable to communicate.

Alternative therapies – treatments that are used in place of conventional medical treatment, often in the hope they will provide a cure.

Burden (of disease) – a measure of the gap between a population's actual health and an ideal level of health based on mortality, morbidity and other quality-of-life indicators.

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, treatment, survivorship and palliative care.

Care coordinator – a generic term used within the health system to describe a position that is responsible for coordinating care for a patient.

In the cancer context it is a health professional nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and where care is primarily located.

In the primary healthcare context it is a health professional assigned to a patient to coordinate patient care beyond a clinical aspect. For example, it may include advocating on behalf of the patient, linking the patient to support services or providing individualised patient education.

Complementary therapies – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life and help people deal with the side effects of cancer.

Cultural competence – describes 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 (Betancourt et al. 2002; Cross et al. 1989).

Culturally safe – A culturally safe environment is one where we feel safe and secure in our identity, culture and community (Australian Human Rights Commission 2011). 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' (Royal Australian College of General Practitioners 2011 p. 2 2011).

Elder – someone who has gained recognition as a custodian of knowledge and lore, and who has permission to disclose knowledge and beliefs.

End-of-life care – a distinct phase of palliative care that is appropriate when a patient's symptoms are increasing and functional status is declining despite anti-cancer therapy.

General or primary (medical) practitioner – the practitioner to whom the patient first presents with symptoms; this may be a general practitioner, an emergency department clinician or a medical professional providing cancer screening services.

Health literacy – the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and healthcare and to take appropriate action (Australian Commission on Safety and Quality in Health Care 2014).

Health professional – a term used in this pathway to refer to a person involved in providing healthcare including doctors, nurses, psychologists, oncologists, Aboriginal and/or Torres Strait Islander Health Workers and counsellors.

Institutional racism – racism that exists in social and political institutions. 'Institutional racism' refers to the ways in which racist beliefs or values have been built into the operations of institutions in such a way as to discriminate against, control and oppress various minority groups (Australian Health Ministers' Advisory Council 2016; McConnachie 1988).

Kinship – Kinship and relationship structures remain important in many Indigenous peoples and communities today, irrespective of where they are geographically located. A person's position in the kinship system establishes their relationship to others and to the universe, prescribing their responsibilities towards other people, the land and natural resources. Some Aboriginal people, especially in the Northern Territory and remote Australia, also follow Moiety and Skin Names kinship relationships.

Lead clinician – the clinician who is responsible for managing patient care. The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Multidisciplinary care – an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and develop an individual treatment plan collaboratively for each patient (Department of Health and Human Services 2007a).

Multidisciplinary team – care team that comprises the core disciplines integral to providing good care. The team is flexible in approach, reflects the patient's clinical and psychosocial needs and has processes to facilitate good communication.

Optimal care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care.

Palliative care – any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

Practice team – a primary healthcare team (or general practice team) that provides care in the general practice setting. It can consist of a range of health professionals such as general practitioners, nurses and Aboriginal and/or Torres Strait Islander Health Workers.

Primary healthcare services – healthcare delivered through the general practice sector, Aboriginal community-controlled health organisations, community health services and state or territory primary healthcare services.

Rehabilitation – comprises multidisciplinary efforts to allow the patient to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

Risk factor – increases the likelihood of developing a health disorder or condition such as cancer.

Shame – the concept of shame in the Aboriginal and Torres Strait Islander community is broader than the non-Indigenous use of the word. The meaning of shame extends to include situations that cause embarrassment or that have associated stigma or negative connotations, often due to attention or circumstances rather than as the result of an action by oneself.

Social and cultural determinants of health – the 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 healthcare and manage their own health (World Health Organization 2005). 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 (Aboriginal and Torres Strait Islander Social Justice Commissioner 2005; Osborne et al. 2013; Reilly et al. 2011)

Supportive care – an umbrella term used to describe services that may be required by those affected by cancer including self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care.

Traditional medicine – defined by the World Health Organization as the 'sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness' (World Health Organization 2000 p. 1). Recent studies have identified that Aboriginal and Torres Strait Islander traditional medicine and healing offers a range of benefits for patients including positive health outcomes, calming effects and improved community trust of mainstream medicine and health services (Panzironi & Anangu Ngangkari Tjutaku Aboriginal Corporation 2013). For these reasons, incorporation of Aboriginal and Torres Strait Islander traditional medicine and healing should be encouraged and supported, wherever practical.

Unconscious bias – how a person's culture, values and motivations influence their practice (Australian Health Ministers' Advisory Council 2016).

References

Aboriginal and Torres Strait Islander Social Justice Commissioner 2005, Social justice report 2005: report of the Aboriginal and Torres Strait Islander Social Justice Commissioner (report no. 3/2005), Human Rights and Equal Opportunity Commission, Sydney.

American Association for Cancer Research; 2017 *Cancer Progress Report 2017* viewed March 2018

http://www.cancerprogressreport.org/.

Atkinson J 2013, *Trauma-informed services and trauma-specific care for Indigenous Australian children,* Resource sheet no. 21. Produced for the Closing the Gap Clearinghouse, Australian Institute of Health and Welfare, Canberra & Australian Institute of Family Studies, Melbourne.

Australian Bureau of Statistics 2011, *Estimates of Aboriginal and Torres Strait Islander Australians*, viewed 24 August 2017, <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3238.0.55.001>.

Australian Bureau of Statistics 2013, *Australian Aboriginal and Torres Strait Islander Health Survey: first results, Australia 2012–13.* (No 4727.0.55.001), 'Ear diseases and hearing problems', Canberra, viewed 24 August 2017, <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/0BBD25C6FF8BDB06CA257C2F001458BF>.

Australian Bureau of Statistics 2016a, *National Aboriginal and Torres Strait Islander Social Survey 2014–15*, Cat No. 4714.0, viewed 24 August 2017, <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~2014-15~Main%20Features~Health%20risk%20factors~12>.

Australian Bureau of Statistics 2016b, *National Aboriginal and Torres Strait Islander Social Survey 2014–15,* Cat No. 4714.0, viewed 24 August 2017, <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~2014-15~Main%20Features~Social%20networks%20and%20wellbeing~4>.

Australian Commission on Safety and Quality in Health Care 2014. *Health literacy: Taking action to improve safety and quality.* Australian Commissionon Safety and Quality in Health Care, Sydney.

Australian Health Ministers' Advisory Council 2017, *A national framework for advance care directives*, AHMAC, Canberra.Australian Health Ministers' Advisory Council 2017, *Aboriginal and Torres Strait Islander health performance framework 2017 report,* AHMAC, Canberra.

Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee 2016, *Cultural Respect Framework 2016 - 2026 for Aboriginal and Torres Strait Islander Health.* AHMAC, Canberra.

Australian Human Rights Commission 2011, *Social justice report,* AHRC, Sydney, viewed 24 August 2017, <https://www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/social-justice-report-3>.

Australian Indigenous Health*Info*Net 2016, *Key facts – traditional healing,* viewed 24 August 2017, <http://www.healthinfonet.ecu.edu.au/related-issues/healing/traditional-healing/key-facts>.

Australian Indigenous Health*Info*Net 2017, *Overview of Aboriginal and Torres Strait Islander health status 2016,* Australian Indigenous Health*Info*Net, Perth.

Australian Institute of Health and Welfare & Australasian Association of Cancer Registries 2003, *Cancer survival in Australia 1992–1997: geographic categories and socioeconomic status* (Cancer series no. 22. AIHW cat. no. CAN 17), AIHW, Canberra.

Australian Institute of Health and Welfare & Cancer Australia 2013, *Cancer in Aboriginal and Torres Strait Islander people of Australia: an overview* (Cancer series no.78. Cat. no. CAN 75), AIHW, Canberra.

Australian Institute of Health and Welfare. 2014. Cancer in Australia: an overview 2014. Cancer series, No 90. Cat. no. CAN 88. Canberra: AIHW

Australian Institute of Health and Welfare 2015, *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015.* Cat. no. IHW 147, AIHW, Canberra.

Australian Institute of Health and Welfare 2016b. Australian Burden of Disease Study: Impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2011. Australian Burden of Disease Study series no. 6. Cat. no. BOD 7. Canberra: AIHW

Australian Institute of Health and Welfare 2016, *Australia's health 2016* (Australia's health series no. 15 Cat. no. AUS 199), AIHW, Canberra.

Australian Institute of Health and Welfare 2017a, *Cancer in Australia: in brief 2017* (Cancer series no. 102. Cat. no. CAN 101. Canberra: AIHW , viewed 3 September 2017 <http://www.aihw. gov.au/publication-detail/?id=60129558546>.

Australian Institute of Health and Welfare 2017b, *Cervical screening in Australia 2014–2015*, Cancer series no. 105. Cat. no. CAN 104. Canberra: AIHW, viewed 17 August 2017, <http://aihw.gov. au/publication-detail/?id=60129559631>.

Australian Institute of Health and Welfare 2017c, *National Bowel Cancer Screening Program: monitoring report 2017*. Cancer series no.104. Cat. no. CAN 103. Canberra: AIHW, viewed 3 September 2017 < https://www.aihw.gov. au/reports/cancer-screening/bowel-cancer-screening-program-monitoring-2017/contents/table-of-contents>.

Australian Institute of Health and Welfare 2017d. BreastScreen Australia monitoring report 2014–2015. Cancer series no. 106. Cat. no. CAN 105. Canberra: AIHW

Australian Institute of Health and Welfare 2018 *Cancer in Aboriginal and Torres Strait Islander people of Australia*, web report, viewed 28 March 2018. <https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians/contents/summary.>

Bainbridge R, McCalman J, Clifford A, Tsey K 2015, *Cultural competency in the delivery of health services for Indigenous people* (Issues paper no. 13. Produced for the Closing the Gap Clearinghouse). AIHW, Canberra & AIFS, Melbourne, viewed 24 August 2017, <http://www.aihw.gov.au/uploadedFiles/ClosingTheGap/Content/Our_publications/2015/ctgc-ip13.pdf>.

Betancourt J, Green AR, Carrillo JE 2002, *Cultural competence in health care: emerging frameworks and practical approaches,* The Commonwealth Fund, viewed 24 August 2017, <http://www.commonwealthfund.org/publications/fund-reports/2002/oct/cultural-competence-in-health-care--emerging-frameworks-and-practical-approaches>.

Binns PL & Condon JR 2006. Participation in cervical screening by Indigenous women in the Northern Territory: a longitudinal study. Medical Journal of Australia 185(9):490–94

Brandes K, Linn AJ, Butow PN, van Weert JCM 2015, 'The characteristics and effectiveness of Question Prompt List interventions in oncology: a systematic review of the literature', *Psycho-Oncology,* vol. 24, no. 3, pp. 245–252.

Cancer Australia 2010, *Complementary and alternative therapies* (position statement), Cancer Australia, Surry Hills, viewed 24 August 2017, <https://canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>.

Cancer Australia 2014, *Review and collation of evidence on programs improving cancer outcomes in Aboriginal and Torres Strait Islander People Project,* Health Outcomes Australia, Glynde.

Cancer Australia 2015, *National Aboriginal and Torres Strait Islander cancer framework,* Cancer Australia, Surry Hills, viewed 24 August 2017, <https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-aboriginal-and-torres-strait-islander-cancer-framework>.

Clinical Oncology Society of Australia 2013, *Position statement: The use of complementary and alternative medicine by cancer patients,* COSA, Sydney.

Condon J 2004, Aboriginal and Torres Strait Islander Primary Health Care Review: Consultant Report No 5: Cancer, Health Services and Indigenous Australians, Commonwealth of Australia, Canberra.

Coory MD, Ho T, Jordan SJ 2013, 'Australia is continuing to make progress against cancer, but the regional and remote disadvantage remains', *Medical Journal of Australia,* vol. 199, no. 9, pp. 605–608.

Coory MD, Muller JM, Dunn NAM & Fagan PS 2002. Participation in cervical screening by women in rural and remote Aboriginal and Torres Strait Islander communities in Queensland. Medical Journal of Australia 177(10):544–47

Council of Australian Governments 2016, *Cultural respect framework 2016–2026 for Aboriginal and Torres Strait Islander Health: a national approach to building a culturally respectful health system*, prepared by the Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee, Canberra.

Cross T, Bazron B, Dennis K, Isaacs M 1989, *Towards a culturally competent system of care: a monograph on effective service for minority children who are severely emotionally disturbed,* Georgetown University Child Development Center, CASSP Technical Assistance Center, Washington, DC, viewed 24 August 2017, <https://www.ncjrs.gov/App/Publications/abstract.aspx?ID=124939>.

Cunningham J 2002, 'Diagnostic and therapeutic procedures among Australian hospital patients identified as Indigenous', *Medical Journal of Australia*, vol. 176, no. 2, pp. 58–62.

Cunningham J, Rumbold AR, Zhang X, Condon JR 2008, Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia, *Lancet Oncol,* vol. 9: 585–95.

Department of Health, *National Immunisation Program Schedule* (from 20 April 2015), Australian Government, viewed 24 January 2017, <http://immunise.health.gov.au/internet/immunise/publishing.nsf/Content/national-immunisation-program-schedule>.

Department of Health 2017a, *Human papillomavirus (HPV),* Australian Government, viewed 23 February 2018, <https://beta.health.gov.au/conditions-and-diseases/hpv-human-papillomavirus>.

Department of Health 2017b, *My life my lead. Opportunities for strengthening approaches to the social determinants and cultural determinants of Indigenous health: report on the national consultations, December 2017*, Commonwealth of Australia, Canberra, viewed 13 February 2018 <http://www.health.gov.au/internet/main/publishing.nsf/Content/indigenous-ipag-consulation>.

Department of Health and Human Services 2007a, *Achieving best practice cancer care: a guide for implementing multidisciplinary care – March 2007,* State Government of Victoria, Melbourne, viewed 24 August 2017, <https://www2.health.vic.gov.au/getfile?sc_itemid=%7b1DBE719B-9B21-48F8-9975-D6AAE0DC090A%7d&title=Achieving%20best%20practice%20cancer%20care,%20A%20guide%20for%20implementing%20multidisc-iplinary%20care%20-%20Mar%202007>.

Department of Health and Human Services 2007b, *Linking cancer care: a guide for implementing coordinated cancer care,* State Government of Victoria, Melbourne, viewed 24 August 2017, <https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-services-framework/care-coordination>.

Diaz A, Whop LJ, Valery PC, Moore SP, Cunningham J, Garvey G, et al. 2015, 'Cancer outcomes for Aboriginal and Torres Strait Islander Australians in rural and remote areas', *The Australian Journal of Rural Health,* vol. 23, no. 1, pp. 4–18.

Garvey G, Beesley VL, Janda M, Jacka C, Green AC, O'Rourke P, et al. 2012, 'The development of a supportive care needs assessment tool for Indigenous people with cancer', *BMC Cancer,* no. 12, p. 300.

Garvey G, Beesley VL, Janda M, O'Rourke PK, Me VY, Hawkes AL, et al. 2015, 'Psychometric properties of an Australian supportive care needs assessment tool for indigenous patients with cancer', *Cancer,* vol. 121, no. 17, pp. 3018–3026.

Garvey G, Cunningham J, Valery PC, Condon J, Roder D, Bailie R, et al. 2011, 'Reducing the burden of cancer in Aboriginal and Torres Strait Islander', *Medical Journal of Australia*, vol. 194, no. 10 pp. 530–531.

Garvey G, Thewes B, He VFY, Davis E, Girgis A, Valery PC, et al. 2016, 'Indigenous cancer patient and staff attitudes towards unmet needs screening using the SCNAT-IP', *Supportive Care in Cancer,* vol. 24, no. 1, pp. 215–223.

Government of South Australia, 2017 *South Australian Aboriginal Cancer Control Plan 2016-21* Department for Health and Ageing, Government of South Australia: Adelaide, viewed March 2018 < http://www.sahealth.sa.gov.au/wps/wcm/connect/f09df30045a67ceb8f8baf9f9859b7b1/SA+Aboriginal+Cancer+Control+Plan+2016_21_Final.pdf?MOD=AJPERES&CACHEID=f09df30045a67ceb8f8baf9f9859b7b1>

Ha JF, Longnecker N 2010, 'Doctor–patient communication: a review', *The Ochsner Journal,* vol. 10, no. 1, pp. 38–43.

Haines IE 2011, 'Managing patients with advanced cancer: the benefits of early referral for palliative care', *Medical Journal of Australia,* vol. 194, no. 3, pp. 107–108.

Hall SE, Bulsara CE, Bulsara MK, Leahy TG, Culbong MR, Hendrie D, Holman CDJ, et al. 2004, 'Treatment patterns for cancer in Western Australia: does being Indigenous make a difference?', *Medical Journal of Australia,* vol. 181, no. 4, pp. 191–194.

Hunt J 2013, *Engaging with Indigenous Australia: exploring the conditions for effective relationships with Aboriginal and Torres Strait Islander communities* (Issues paper no. 5. Produced for the Closing the Gap Clearinghouse), AIHW, Canberra & AIFS, Melbourne, viewed 24 August 2017, < https://www.aihw.gov.au/reports/indigenous-australians/engaging-with-indigenous-australia-exploring-the/contents/table-of-contents >.

Institute of Medicine & National Research Council 2006, *From cancer patient to cancer survivor: lost in transition,* The National Academies Press, Washington, DC.

Jong KE, Smith DP, Yu XQ, O'Connell DL, Goldstein D, Armstrong BK 2004, 'Remoteness of residence and survival from cancer in New South Wales', *Medical Journal of Australia,* vol. 180, no. 12, pp. 618–622.

McGrath P 2006, 'The biggest worry…': research findings on pain management for Aboriginal people in Northern Territory, Australia', *Rural and Remote Health,* vol. 6, no. 3, p. 549.

Mooi JK, Whop LJ, Valery PC, Sabesan SS 2012, 'Teleoncology for Indigenous patients: the responses of patients and health workers', *Australian Journal of Rural Health*, no. 20, pp. 265–269.

National Aboriginal Community Controlled Health Organisation 2017, *Definitions,* viewed 13 February 2018, <http://www.naccho.org.au/about/aboriginal-health/definitions/>

National Health and Medical Research Council 2003, *Values and ethics: guidelines on ethical conduct in Aboriginal and Torres Strait Islander health research,* Commonwealth of Australia, Canberra, viewed 24 August 2017, <https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e52.pdf>.

National Health and Medical Research Council, Australian Research Council & Australian Vice-Chancellors' Committee 2007, *National statement on ethical conduct in human research 2007 (Updated May 2015),* Commonwealth of Australia, Canberra, viewed 24 August 2017, <https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72_national_statement_may_2015_150514_a.pdf>.

National Notifiable Diseases Surveillance System Annual Report Working Group 2016, Australia's notifiable disease status 2014: annual report of the National Notifiable Diseases Surveillance System, *Communicable Diseases Intelligence,* vol. 40, no. 1, E48–E145.

Osborne K, Baum F, Brown L 2013, *What works?: a review of actions addressing the social and economic determinants of Indigenous health* (Issues paper no. 7, produced for the Closing the Gap Clearinghouse), AIHW, Canberra & AIFS, Melbourne, viewed 24 August 2017, < https://aifs.gov.au/publications/what-works>.

Palliative Care Australia 2005, *Standards for providing quality palliative care for all Australians,* Palliative Care Australia, Deakin, viewed 24 August 2017, <http://palliativecare.org.au/wp-content/uploads/2015/07/Standards-for-providing-quality-palliative-care-for-all-Australians.pdf>.

Panzironi F, Anangu Ngangkari Tjutaku Aboriginal Corporation 2013, *Hand in hand: report on Aboriginal traditional medicine,* Anangu Pitjantjatjara Yankunytjatjara Lands, ANTAC, viewed 24 August 2017, <http://antac.org.au/wp-content/uploads/2016/04/Hand-in-Hand.pdf>.

Peppercorn JM, Weeks JC, Cook EF, Joffe S 2004, 'Comparison of outcomes in cancer patients treated within and outside clinical trials: conceptual framework and structured review', *Lancet,* vol. 363, no. 9405, pp. 263–270.

Pitkethly M, Macgillivray S, Ryan R 2008, 'Recordings or summaries of consultations for people with cancer', *The Cochrane Database of Systematic Reviews,* no. 3, CD001539.

Reilly RE, Cincotta M, Doyle J, Firebrace BR, Cargo M, van den Tol G, et al. 2011, 'A pilot study of Aboriginal health promotion from an ecological perspective', *BMC Public Health,* no. 11, p. 749.

Roder D, Webster F, Zorbas H, Sinclair S 2012, 'Breast screening and breast cancer survival in Aboriginal and Torres Strait Islander women of Australia', *Asian Pacific Journal of Cancer Prevention,* vol. 13, no. 1, pp. 147–155.

Royal Australian College of General Practitioners 2011, *Cultural awareness education and cultural safety training,* RACGP, Canberra, viewed 24 August 2017, <http://www.racgp.org.au/yourracgp/faculties/aboriginal/education/resources-for-gps-and-practice-staff/cultural-awareness/>.

Shahid S, Bleam R, Bessarab D, Thompson SC 2010, '"If you don't believe it, it won't help you": use of bush medicine in treating cancer among Aboriginal people in Western Australia', *Journal of Ethnobiology and Ethnomedicine,* no. 6, p. 18.

Sjoquist KM, Zalcberg JR 2013, 'Clinical trials – advancing national cancer care', *Cancer Forum,* vol. 37, no. 1, viewed 24 August 2017, <http://cancerforum.org.au/forum/2013/march/clinical-trials-advancing-national-cancer-care/>.

Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. 2010, 'Early palliative care for patients with metastatic non-small-cell lung cancer', *The New England Journal of Medicine,* vol. 363, no. 8, pp. 733–742.

The Kirby Institute 2016. *Bloodborne viral and sexually transmitted infections in Aboriginal and Torres Strait Islander people: surveillance and evaluation report 2016,* The Kirby Institute, UNSW Australia, Sydney.

The Lowitja Institute 2014, *Cultural determinants roundtable: background paper,* viewed 24 August 2017, <http://www.lowitja.org.au/sites/default/files/docs/Cultural-Determinants-Roundtable-Background-Paper.pdf>.

Thewes B, Davis E, Girgis A, Valery PC, Giam K, Hocking A, et al. 2016, 'Routine screening of Indigenous cancer patients' unmet support needs: a qualitative study of patient and clinician attitudes', *International Journal for Equity in Health,* no. 15, p. 90.

Treloar C, Gray R, Brener L, Jackson C, Saunders V, Johnson P, et al. 2013, 'Health literacy in relation to cancer: addressing the silence about and absence of cancer discussion among Aboriginal people, communities and health services', *Health & Social Care in the Community,* vol. 21, no. 6, pp. 655–664.

Valery PC., Bernardes CM., Beesley VL. Hawkes AL., Baade PD., Garvey G. 2016. Unmet supportive care needs of Australian Aboriginal and Torres Strait Islanders with cancer: a prospective, longitudinal study. Support Care Cancer 25(3):869-877.

Whop LJ, Garvey G, Baade P, Cunningham J, Lokuge K, Brotherton JM et al. 2016. The first comprehensive report on Indigenous Australian women's inequalities in cervical screening: A retrospective registry cohort study in Queensland, Australia (2000–2011). Cancer 122 (10):1560–69

World Cancer Research Fund International 2017, *Our cancer prevention recommendations – body fatness*, viewed 22 June 2017, < https://www.wcrf.org/int/research-we-fund/our-cancer-prevention-recommendations/body-fatness>.

World Health Organization 2000, *General guidelines for methodologies on research and evaluation of traditional medicine,* WHO, Geneva viewed 24 January 2017, <http://apps.who.int/iris/bitstream/10665/66783/1/WHO_EDM_TRM_2000.1.pdf>.

World Health Organization 2005, *Action on the social determinants of health: learning from previous experiences. A background paper prepared for the Commission on Social Determinants of Health,* WHO, Geneva, viewed 24 August 2017, <http://www.who.int/social_determinants/resources/action_sd.pdf>.

Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leighl N, Oza A, et al. 2014, 'Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial', *Lancet,* vol. 383, no. 9930, pp. 1721–1730.

Additional resources used to prepare this OCP

Abbott P, Dave D, Gordon E, Reath J 2014, 'What do GPs need to work more effectively with Aboriginal patients? Views of Aboriginal cultural mentors and health workers', Australian Family Physician, vol. 43, no. 1, pp. 58–63.

Aboriginal & Torres Strait Islander Health Branch, Queensland Health 2015, *Sad news, sorry business: guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying,* State of Queensland, Brisbane.

Australian Bureau of Statistics 2013, *Estimates of Aboriginal and Torres Strait Islander Australians, June 2011* (No. 3238.0.55.001), ABS, Canberra, viewed 24 August 2017, <http://www.abs.gov.au/AUSSTATS/abs@. nsf/Lookup/3238.0.55.001Main+Features1June%202011?OpenDocument>.

Australian Commission on Safety and Quality in Health Care 2013, *Consumers, the health system and health literacy: taking action to improve safety and quality* (consultation paper), ACSQHC, Sydney.

Australian Commission on Safety and Quality in Health Care 2016, *Overview: Guide to better care for Aboriginal and Torres Strait Islander communities,* ACSQHC, Sydney.

Australian Institute of Health and Welfare 2011, *Access to health services for Aboriginal and Torres Strait Islander people*. Cat.no. IHW 46, AIHW, Canberra, viewed 24 August 2017, < https://www.aihw.gov.au/reports/indigenous-australians/access-to-health-and-services-for-aboriginal-and-t/contents/table-of-contents>.

Begbie S, Underhill C 2007, 'Cancer services to be proud of in rural Australia: lessons learnt from the Clinical Oncological Society of Australia Cancer Service Audit', *Regional and Rural Cancer Care*, vol. 31, no. 2, viewed 24 August 2017, <http://cancerforum.org.au/forum/2007/july/cancer-services-to-be-proud-of-in-rural-australia-lessons-learnt-from-the-clinical-oncological-society-of-australia-cancer-service-audit/>.

Cancer Institute NSW 2015, *Cancer treatment side effects: a guide for Aboriginal health workers*, Sydney, viewed 24 August 2017, <https://www.cancerinstitute.org.au/getattachment/c361e0e4-7d87-4c37-9d0c-364ef1e57b4f/AHW-Booklet.pdf>.

Carson B, Dunbar T, Chenhall RD, Bailie R (eds) 2007, *Social determinants of indigenous health,* Allen & Unwin, Crows Nest.

Cunningham J, Rumbold AR, Zhang X, Condon JR 2008, 'Incidence, aetiology, and outcomes of cancer in Indigenous people in Australia', *The Lancet. Oncology,* vol. 9, no. 6, pp. 585–595.

Department of Health and Human Services 2010, *Improving the patient experience for Aboriginal people in emergency departments*, State Government of Victoria, Melbourne.

Department of the Prime Minister and Cabinet (n.d.). *Closing the Gap: Prime Minister's report 2017,* Commonwealth of Australia, Canberra, viewed 24 August 2017, <https://www.pmc.gov.au/resource-centre/indigenous-affairs/closing-gap-prime-ministers-report-2017>.

Dwyer J, Kelly J, Willis E, et al. 2011, *Managing two worlds together: city hospital care for country Aboriginal people: project report,* The Lowitja Institute, Melbourne, viewed 24 August 2017, <http://www.lowitja.org.au/sites/default/files/docs/M2WT_Project_Report.pdf>.

Maddocks I, Rayner RG 2003, 'Issues in palliative care for Indigenous communities', *The Medical Journal of Australia*, vol. 179, no. 6 Suppl, S17–19, viewed 24 August 2017, <https://www.mja.com.au/journal/2003/179/6/issues-palliative-care-indigenous-communities>.

New South Wales, Department of Community Services & Aboriginal Services Branch 2009, *Working with Aboriginal people and communities: a practice resource*, Government of New South Wales, Ashfield, viewed 24 August 2017, <http://www.carersaustralia.com.au/storage/2011Working%20with%20Aboriginal%20People%20and%20Communities.pdf>.

North Coast Area Health Service 2009, *Cultural respect and communication guide: a resource to assist sexual health service delivery to Aboriginal communities*, New South Wales North Coast Area Health Service, North Coast Area.

Oxfam Australia 2007, *Aboriginal and Torres Strait Islander cultural protocols*, viewed 24 August 2017, <https://www.oxfam.org.au/wp-content/uploads/2015/11/2015-74-atsi-cultural-protocols-update_web.pdf>.

The Aboriginal and Torres Strait Islander Cultural Capability Team 2014, *Aboriginal and Torres Strait Islander patient care guideline*, State of Queensland, Brisbane (Queensland Health), viewed 24 August 2017, <https://www.health.qld.gov.au/__data/assets/pdf_file/0022/157333/patient_care_guidelines.pdf>

Ware V-A 2013, *Improving the accessibility of health services in urban and regional settings for Indigenous people* (resource sheet no. 27, produced for the Closing the Gap Clearinghouse), AIHW, Canberra & AIFS, Melbourne, viewed 24 August 2017, <http://www.aihw.gov.au/uploadedFiles/ClosingTheGap/Content/Publications/2013/ctgc-rs27.pdf>.

Wodonga Institute of TAFE, Australia, Mercy Health Service Albury (Palliative Care) & Mungabareena Aboriginal Corporation 2004, *Providing culturally appropriate palliative care to indigenous Australians: resource kit*, Australian Government Department of Health and Ageing, Canberra.

World Health Organization 2008, *Closing the gap in a generation: health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health,* Geneva, viewed 24 August 2017, <http://apps.who.int/iris/bitstream/10665/43943/1/9789241563703_eng.pdf>.

Zon R, Frame J, Neuss M, Page R, et al 2016, 'American Society of Clinical Oncology policy statement on clinical pathways in oncology. American Society of Clinical Oncology', *Journal of Oncology Practice,* vol. 12, no. 3, pp. 261–266.

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Other stakeholders invited to provide feedback

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Aboriginal and Torres Strait Islander Higher Education Advisory Council (ATSIHEAC)

Aboriginal Health and Medical Research Council of New South Wales (AH&MRC)

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Aboriginal Health Council of Western Australia (AHCWA)

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Aboriginal Medical Services Alliance Northern Territory (AMSANT)

Advisory Group on Aboriginal and Torres Strait Islander Statistics

All state and territory health departments

Allied Health Professions Australia

Asian-Pacific Hepato-Pancreato-Biliary Association

Australasian Association of Nuclear Medicine Specialists

Australasian College for Emergency Medicine (ACEM)

Australasian Pancreatic Club

Australia and New Zealand Head and Neck Cancer Society

Australia and New Zealand Hepatic, Pancreatic and Biliary Association

Australia and New Zealand Melanoma Trials Group

Australian and New Zealand Gastric and Oesophageal Surgery Association

Australian and New Zealand Society of Palliative Care

Australian Bureau of Statistics (ABS)

Australian Cancer Consumer Network

Australian Chapter of Palliative Medicine, RACP

Australian College of Nursing (ACN)

Australian College of Rural and Remote Medicine (ACRRM)

Australian Human Rights Commission

Australian Indigenous Doctors Association (AIDA)

Australian Indigenous Health*Info*Net

Australian Institute of Aboriginal and Torres Strait Islander Studies

Australian Institute of Health and Welfare (AIHW)

Australian Institute of Radiography

Australian Medical Association

Australian National University Indigenous Health Unit

Australian New Zealand Gynaecological Oncology Group

Australian Society Gynaecological Oncologists

Bowel Cancer Australia

Brain Tumour Alliance Australia

Breast Cancer Network Australia

Cancer Action Victoria

Cancer Council Australia

Cancer Nurses Society of Australia (CNSA)

Cancer Voices Australia

CanSpeak

CC National Publications Group

Centre for Aboriginal Primary Health Care Training, Education and Research

Charles Darwin University Australian Centre for Indigenous Knowledge and Education

Chris O'Brien Lifehouse

Clinical Oncological Society of Australia (COSA)

Closing the Gap Indigenous Health Leadership Group

Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)

Cooperative Trials Group for Neuro-Oncology

Department of Education and Training

Dietitians Association of Australia

Edith Cowan University Kurongkurl Katitjin Centre for indigenous Australian Education and Research

First People's Disability Network (FPDN)

Flinders University Poche Centre for Indigenous health and wellbeing

Gastroenterological Society of Australia

Haematology Society of Australia and New Zealand (HSANZ)

Indigenous Allied Heath Australia

Interventional Radiology Society of Australasia

James Cook University

Kimberley Aboriginal Medical Services Council (KAMSC)

La Trobe University Office of Indigenous Strategy and Education

Leukaemia Foundation

Lowitja Institute

Lung foundation

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Melanoma Patients Australia

Melbourne Melanoma Project

Menzies School of Health Research

Movember Foundation

National Aboriginal and Torres Strait Islander Legal Services (NATSILS)

National Aboriginal and Torres Strait Islander Women's Alliance (NATSIWA)

National Aboriginal Community Controlled Health organisation (NACCHO)

National Association of Aboriginal and Torres Strait Islander Physiotherapists

National Breast Cancer Foundation

National Centre for Indigenous Excellence (NCIE)

National Congress of Australia's first peoples

National Family Violence Prevention Legal Services (FVPLS) Forum

National Rural Health Alliance

Ovarian Cancer Australia

Palliative Care Australia

Primary Health Networks

Prime Minister's Indigenous Advisory Council

Prostate Cancer Foundation of Australia

Queensland Aboriginal and Islander Health Council (QAIHC)

Royal Australasian College of Dental Surgeons

Royal Australian College of General Practitioners (RACGP)

Royal Australian College of General Practitioners (RACGP), National Aboriginal & Torres Strait Islander Health Faculty

SNAICC – National Voice for our Children

South Australian Health & Medical Research Institute (SAHMRI)

State and territory BreastScreen services

The Alan Walker Cancer Centre

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The Department of the Prime Minister and Cabinet (PM&C)

The Healing Foundation

The National Aboriginal and Torres Strait Islander Health Equality Council (NATSIHEC)

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The Royal Australasian College of Surgeons (RACS)
The Royal Australian and New Zealand
College of Obstetricians and Gynaecologists
(RANZCOG)
The Royal Australian and New Zealand College
of Psychiatrists (RANZCP)
The Royal Australian and New Zealand College
of Radiologists (RANZCR)
The Royal College of Pathologists of Australasia
The University of Adelaide Yaitya Purruna
Indigenous Health unit
The University of Melbourne Poche Centre
for Indigenous health
The University of Queensland Poche Centre
for Indigenous Health
The University of Sydney Poche Centre
for Indigenous health
The University of Western Australia Poche
Centre for Indigenous Health
The Aboriginal and Torres Strait Islander Health
Advisory Committee (ATSIHAC)
University of New South Wales Muru Marri
University of South Australia
Victorian Aboriginal Community Controlled
Health Organisation Inc (VACCHO)
Victorian Comprehensive Cancer Centre (VCCC)
Winnunga Nimmityjah Aboriginal Health Service

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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