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

Draft for National Public Consultation
Statement of acknowledgement

We acknowledge the traditional owners of the country throughout Australia and their continuing connection to land, sea and community. We pay our respects to them and their cultures and to Elders both past and present.

We recognise that ‘Aboriginal and Torres Strait Islander people’ is the preferred term for referring to Aboriginal people and Torres Strait Islanders collectively. This term recognises the distinct cultures, languages and homelands of Australia’s Indigenous communities.
Context

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 (OCP) 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).

Cancer Australia then 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 program of work.

This pathway provides guidance about providing culturally competent 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 who are, on average, 30 per cent more likely to die from cancer than non-Indigenous Australians (Australian Institute of Health and Welfare 2017a). Cancer places a heavy burden not only on those diagnosed with the disease but also their families, Elders and carers.

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). There is a high incidence of cancers that are preventable and are also more likely to be fatal (for example, lung 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 and over is about 40 per cent, compared to about 14% in non-Indigenous Australians (Australian Bureau of Statistics 2016a). Aboriginal and Torres Strait Islander people also have high levels of a number of other modifiable risk factors for cancer including obesity, lack of exercise, risky levels of alcohol consumption and hepatitis B and C infection (Cancer Australia 2015, National Notifiable Diseases Surveillance System Annual Report Working Group 2016, The Kirby Institute 2016).
Generally, Aboriginal and Torres Strait Islander people are less likely to participate in cancer screening programs (Australian Institute of Health and Welfare & Cancer Australia 2013), 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 receive adequate treatment or be hospitalised for cancer (Australian Institute of Health and Welfare 2015). These factors and overall poorer survival are arguably most significantly influenced by the social and cultural determinants of health. Culture has a strong link to health and wellbeing. Stronger connections to culture and country build stronger individual and collective identities, and improved outcomes across the other determinants of health including education, economic stability and community safety (The Lowitja Institute 2014).

For Aboriginal and Torres Strait Islander people, the social and cultural determinants of health may include marginalisation from the dominant culture, racism and living in remote areas (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 2016b).

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 impact on access to health services, with around one in seven (14 per cent) having avoided situations in the last 12 months 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 all 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 OCP 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. 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.

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 are 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 people
- understanding the social 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 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 (Council of Australian Governments 2016).

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), as well as for 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 opportunity to improve health outcomes for Aboriginal and Torres Strait Islander people by addressing this at both the individual and system level (Council of Australian Governments 2016).

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.

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

- care coordinators and/or navigators
- Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners
- Aboriginal and 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 as 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


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.

For Aboriginal and Torres Strait Islander patients, it is essential that the team includes an expert in providing culturally appropriate care to this population (Department of Health and Human Services 2007a).

The multidisciplinary team should consider the patient’s personal, social and cultural circumstances and factor these into the 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.

Considerations for Aboriginal and Torres Strait Islander people affected by cancer that may require referral and extra support include:

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

Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.
All members of the multidisciplinary team have a role in providing supportive care. In addition, support from family, friends, Elders, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

An important step in providing supportive care is to identify, by routine and systematic screening (using a validated screening tool) of the patient and family, views on issues they require help with for optimal health and quality-of-life outcomes. This should occur at key steps along the care pathway.

**Further information**
- The Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) is a useful tool for identifying the needs of adult cancer patients. Learn about the SCNAT-IP tool at [http://www.scnatip.org/](http://www.scnatip.org/).

**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 a culturally competent workforce (through additional training, skills and knowledge attainment). Gender, 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 appropriate 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 in Aboriginal and Torres Strait islander populations (Australian Indigenous HealthInfoNet 2017), some Aboriginal and Torres Strait Islander people may have an established or ongoing relationship with a primary healthcare 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 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 Torres Strait Islander Health Worker, Health Practitioner and/or Hospital Liaison Officer if the person does not attend clinic appointments
- discussing management of shared care, including contributing to the development of a chronic disease and mental health care 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 doctors
- 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 professional access to continued professional development opportunities
- improving the provision of relevant support services, such as by 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 or Torres Strait Islander Health Worker or other identified Aboriginal 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 transition and continuity of care to the patient.

Further information

- The National Aboriginal Community Controlled Health Organisation 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:

- 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).

Communication may be facilitated by the use of appropriate technology such as telehealth and other resources/tools.

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 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 personal benefit from the intervention, there is evidence that outcomes for participants 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 participation in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participation 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 the benefits of the clinical trials.

*Further information*
• See the National Health and Medical Research Council’s Ethical guidelines for research involving Aboriginal and Torres Strait Islander people at <https://www.nhmrc.gov.au/health-ethics/ethical-issues-and-further-resources/ethical-guidelines-research-involving-aboriginal-/>.
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.

**Healthcare environment**

The delivery of optimal cancer care begins with creating a safe, welcoming and inclusive environment for all patients. 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)
- 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
- the presence and employment of Aboriginal and Torres Strait Islander people in health services across 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. (Cancer Australia 2015). 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.

The use of teleoncology may be considered as an acceptable model of care for Aboriginal and Torres
Strait Islander patients (Mooi et al. 2012). Health professionals who provide teleoncology services need to be adaptive to the needs of individual patients and local communities in order 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 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 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 areas, 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 …’)
- encouraging expression of individual concerns, needs and emotional states, recognising that patients may feel 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 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:
- establish the preferences of the patient as to whether they’d like an Aboriginal and 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
- 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). As hearing loss impacts on many social determinants such as literacy attainment, communication strategies may require further individualisation.

Health professionals should avoid using traditional languages, creole words or titles used between Aboriginal and Torres Strait Islander people (such as ‘Aunty’ or ‘Uncle’) unless they have a clear understanding or are invited to do so by the patient.

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 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


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 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 professional, where possible
- offering referral to an alternative service provider when a choice of male or female 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 men’s or women’s business topics in the presence of members of the opposite gender
- avoiding assumptions by asking the person what could help them feel more comfortable.

Health literacy

Higher levels of health literacy 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 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’ (Cancer Australia 2015; Treloar et al. 2013).

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 culturally appropriate resources at key times (for example, screening information during regular general or primary practitioner appointments or consumer guides at the time of diagnosis)
• engagement of cancer champions or survivors to openly talk about cancer, 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.

Further information
• HealthInfoNet is a web portal on Aboriginal and Torres Strait Islander health topics available at <http://www.healthinfonet.ecu.edu.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 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 care pathway for cancer

The OCPs outline the seven critical steps in the patient journey.

While the seven steps appear in a linear model, in practice, patient care does not always occur in this way 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).

The aim of the OCP for Aboriginal and Torres Strait Islander people with cancer is to help guide system responsiveness to cultural needs.

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 are available throughout this document to the OCPs for the cancers with the greatest burden on Aboriginal and Torres Strait Islander people with respect to morbidity and mortality, and the 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.
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 and cervical cancers) (Australian Institute of Health and Welfare 2017a)
- 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 and Cancer Australia 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 (Australian Institute of Health and Welfare & Cancer Australia 2013)
- lower participation in cancer screening programs (Australian Institute of Health and Welfare & Cancer Australia 2013)
- 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 annual 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:


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
- 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 (World Cancer Research Fund International 2017).

The health gap for Aboriginal and Torres Strait Islander people is impacted 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.

#### Cancer risk reduction

General risk reduction advice includes:

- quitting smoking
- maintaining a healthy body weight
- exercising regularly, 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
- avoiding relying on supplements
- breastfeeding for six months if possible.

#### 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 <www.quit.org.au>)
- nicotine replacement therapy and other pharmacological agents.

Further information


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 2017).

Individual assessment

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

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 initially occur in primary care. Cancer risk assessment should be repeated when major risk factors change (for example, new family cancer history). For patients with 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
- referral to a specialist to plan appropriate surveillance and management.

Further information

- 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 should encourage participation in the screening programs appropriate to the individual’s age and risk, as screening can significantly impact on 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 & Cancer Australia 2017c; Australian Institute of Health and Welfare & Cancer Australia 2013; Roder et al. 2012). 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 discussion 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 improve the quality of screening services for Aboriginal and Torres Strait Islander people (Cancer Australia 2015).

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 (Cancer Australia 2015). This can be addressed by establishing rapport and trust with the patient and family and reassuring people that health professionals abide by a privacy code of conduct.

Having dedicated personnel and systems for setting up regular and timely referrals and follow-up appointments may greatly assist with improving participation levels in screening programs. 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>. Note: bowel cancer screening is not delivered through Primary Health Networks.

1.4 Early detection
Timely diagnosis is vital to improving cancer survival. Key factors that may impact on detection in Aboriginal and Torres Strait Islander people include:

• comorbidities masking cancer symptoms
• 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).

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

**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:
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, 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 (Cancer Australia 2015)
- have family and community responsibilities
- experience feelings of 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 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 completing investigations and referral to specialists

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 patient 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 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 healthcare care coordinator and Aboriginal and 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 (Cancer Australia 2015). An individualised clinical assessment is required to assess supportive care needs and should optimally be undertaken in collaboration with an Aboriginal and 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.

Note that some people may experience shame, including shyness from the heightened attention associated with cancer investigations and follow-up or care. One avenue to minimise 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). This tool examines the needs of adult cancer patients across five domains (psychological, health system and information, physical and daily living, patient care and support, and sexuality needs) and should be routinely used by health professionals throughout the cancer pathway (Garvey et al. 2012).

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

• treatment for physical symptoms
• help with the emotional distress of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems, stress and adjustment difficulties
• 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 tool at <http://www.scnatip.org/>.

2.4.2 Communication with the patient, family and carer
For information on communication with the patient, family and carer, refer to the Cross-cultural communication section.

Further information
• Cancer information for Aboriginal and Torres Strait Islander people from Cancer Council NSW: <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/interpreteguide4thedition/>.

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:
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

There are a range of diagnostic tests, assessments and investigations that 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 by an Aboriginal 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 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 as 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

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 healthcare care coordinator may have a key role.

The cancer care coordinator is responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase. The care coordinator may change over the course of the pathway. If a specialised care coordinator is not available, this responsibility should be assigned to another team member. This is important because effective care coordination has been cited as a key factor for enhancing Aboriginal and Torres Strait Islander patient experiences and for promoting ongoing engagement with health services (Cancer Australia 2015).

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 manner.

An Aboriginal and 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 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 (Department of Health and Human Services 2007a). This may be an Aboriginal and 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 by the use of 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 [www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au).
- The National Health and Medical Research Council’s *Values and ethics: guidelines on ethical conduct in Aboriginal and Torres Strait Islander health research* is available at [https://www.nhmrc.gov.au/guidelines-publications/e52](https://www.nhmrc.gov.au/guidelines-publications/e52).
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 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 the multidisciplinary team meeting
- 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 the contact details of the care coordinators 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 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 Torres Strait Islander Health Worker or Aboriginal and Torres Strait Islander 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:
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 as there can be 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 interpretation of health, illness and treatment may impact on 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
- engagement with identified health professionals, such as an Aboriginal and 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

### 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 the patient 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’ or ‘not going to get better’ may be more accepted due to spiritual belief 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 patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.
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

- The National Health and Medical Research Council’s Values and ethics: guidelines on ethical conduct in Aboriginal and Torres Strait Islander health research is available at <https://www.nhmrc.gov.au/guidelines-publications/e52>.

4.6 Traditional medicine, complementary therapies and alternative therapies

Many Aboriginal 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 provision 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

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 culturally appropriate pain tool for the local communities
• 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

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 patient 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


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 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 & 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

Cancer survivors 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 cancer survivors cope with life beyond their acute treatment.

Many cancer survivors 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. Survivors may experience altered relationships and may encounter practical issues, including difficulties with return 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 HealthInfoNet 2016).

Challenges specific to Aboriginal and Torres Strait Islander cancer survivors may include 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 (Cancer Australia 2015).

Survivors need to see a specialist for regular follow-up, often for five or more years after cancer treatment finishes. The Institute of Medicine, in its report From cancer patient to cancer survivor: Lost in transition, describes four essential components of survivorship care (Institute of Medicine and 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 management of symptoms, distress and practical issues)
- coordination of care between all providers to ensure the patient’s needs are met.

Strategies to assist Aboriginal and Torres Strait Islander patients with the transition to survivorship include:

- engaging Aboriginal and 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 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
Upon completion of initial treatment, 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 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 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 at the completion of the primary treatment 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 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
• The National Health and Medical Research Council’s Values and ethics: guidelines on ethical conduct in Aboriginal and Torres Strait Islander health research is available at <https://www.nhmrc.gov.au/guidelines-publications/e52>.
• 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 return to work or study may require extra support.
- Increased community support may be required as the patient recovers from treatment.

Further information


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:

- 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:
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 competent 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 level of disease and the treatment options available.

Advance care planning should be initiated as there can be 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’ or ‘not going to get better’ may be more accepted due to spiritual belief around the life cycle. Obtain guidance about passing from the Aboriginal and Torres Strait Islander Health Worker, Aboriginal and Torres Strait Islander 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 patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

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
- The National Health and Medical Research Council’s Values and ethics: guidelines on ethical conduct in Aboriginal and Torres Strait Islander health research is available at <https://www.nhmrc.gov.au/guidelines-publications/e52>.

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
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 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 and 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 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:
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 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 involved, referral to palliative care 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 engagement with the 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 Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Hospital Liaison Officer, wherever possible.

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 belief 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, consent and 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, polices 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 patients and carers to Palliative Care Australia at [www.palliativecare.org.au](http://www.palliativecare.org.au).

### 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
- availability and transfer of medical equipment
- liaising 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 practice, and the multidisciplinary palliative care team should work with the patient, their family and carers to develop strategies to manage 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 that:

- there are significant cultural practices regarding which family members (which may include Aboriginal and 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 for the local communities
• 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.

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, as well as written copies supplied to take home.

Further information

7.1.3 Practices around death and dying

The practices observed around death and dying vary significantly between both 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 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 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

- The National Health and Medical Research Council’s *Values and ethics: guidelines on ethical conduct in Aboriginal and Torres Strait Islander health research* is available at <https://www.nhmrc.gov.au/guidelines-publications/e52>.
- 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 impacting on 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 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*

### 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 (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 an 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 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:
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 as they are the most frequently diagnosed cancers (incidence) in Aboriginal and Torres Strait Islander populations.

Breast  Colorectal (bowel and rectal)  Head & 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:

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

### 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.

### 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.

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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.
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.

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

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

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.

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.


Optimal care pathway for people with colorectal cancer

Quick reference guide

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

**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.

**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.

**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 fluorodeoxyglucose 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

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.

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

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

**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.

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

**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.

**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 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 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.


This work is available at: www.cancer.org.au/ocep
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:

**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:**
- 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.

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

Step 4
Treatment:
Establish intent of treatment:
- curative
- anti-cancer therapy to improve quality of life and/or prolongation 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.


This work is available at: www.cancer.org.au/ocp
**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:

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Prevention and early detection</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prevention:</strong></td>
<td><strong>Risk factors include:</strong></td>
</tr>
<tr>
<td>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.</td>
<td>• chronic HCV infection</td>
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<tr>
<td>• HBV infection</td>
<td></td>
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<tr>
<td>• a family history of HCC</td>
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<tr>
<td>• cirrhosis of the liver of any cause.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 2</th>
<th>Presentation, initial investigations and referral</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Signs and symptoms:</strong></td>
<td>Tests should be conducted within two to three days of symptom discovery.</td>
</tr>
<tr>
<td>The following signs and symptoms should be investigated:</td>
<td><strong>Referral:</strong> 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.</td>
</tr>
<tr>
<td>• right upper quadrant abdominal pain or discomfort</td>
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<tr>
<td>• a hard lump on the right side of the abdomen</td>
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<tr>
<td>• worsening liver failure (jaundice, ascites, portal hypertension)</td>
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<tr>
<td>• constitutional symptoms</td>
<td></td>
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<tr>
<td>• the presence of multiple signs and symptoms.</td>
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<table>
<thead>
<tr>
<th>Step 3</th>
<th>Diagnosis, staging and treatment planning</th>
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</thead>
<tbody>
<tr>
<td><strong>Diagnosis:</strong></td>
<td><strong>Communication – lead clinician to:</strong></td>
</tr>
<tr>
<td>The following sequence of investigations is suggested:</td>
<td>• explain to the patient/carer who they are being referred to and why</td>
</tr>
<tr>
<td>• four-phase contrast-enhanced computed tomography (CT) scan.</td>
<td>• support the patient and carer while waiting for specialist appointments.</td>
</tr>
<tr>
<td>• magnetic resonance imaging (MRI) with contrast in patients who cannot tolerate CT contrast or where diagnostic uncertainty remains</td>
<td></td>
</tr>
<tr>
<td>• contrast-enhanced ultrasound, in select cases.</td>
<td></td>
</tr>
<tr>
<td>If diagnostic uncertainty still remains, conduct:</td>
<td><strong>Treatment planning:</strong> All patients with suspected or proven HCC should be discussed by a multidisciplinary team before treatment begins.</td>
</tr>
<tr>
<td>• positron emission tomography (PET)</td>
<td><strong>Research and clinical trials:</strong> Consider enrolment where available and appropriate.</td>
</tr>
<tr>
<td>• a liver biopsy (particularly if no surgery is planned).</td>
<td></td>
</tr>
<tr>
<td><strong>Staging:</strong> Staging parameters include imaging (metastases and vascular invasion), Eastern Cooperative Oncology Group (ECOG) status and Child–Pugh score.</td>
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</tr>
</tbody>
</table>

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.

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.aasl.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.


This work is available at: www.cancer.org.au/oCP
Optimal care pathway for people with lung cancer

Quick reference guide

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

1. **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.

2. **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.

3. **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:**
     - explain to the patient/carer who they are being referred to and why
     - support the patient and carer while waiting for specialist appointments.

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

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**Step 4**

Treatment:
- Establish intent of treatment:
  - curative
  - anti-cancer therapy to improve quality of life and/or prolong survival 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/locally advanced 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.


**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)

**Communication – lead clinician to:**
- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

**Step 6**

Managing recurrent, residual and metastatic disease

**Detection:** Most recurrent or metastatic disease will be detected via routine follow-up. Treatment will depend on the location and extent of disease, previous management and the patient’s preferences.

**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.


This work is available at: [www.cancer.org.au/ocp](http://www.cancer.org.au/ocp)
Optimal care pathway for men with prostate cancer

Quick reference guide

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

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

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

Step 2 Presentation, initial investigations and referral

Signs and symptoms
- The majority of men presenting with prostate cancer have no symptoms.
- Symptoms 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.

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.

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

Endorsed by Australian Government Cancer Australia

Cancer Council
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.


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


This work is available at: www.cancer.org.au/ocep
Glossary

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

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

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

**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).

Elder – an Aboriginal or Torres Strait Islander Elder is 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 the general practitioner, an emergency department clinician or a medical professional providing cancer screening services.

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

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 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 community is broader than the non-Indigenous use of the word. The meaning of shame extends to include embarrassment in certain situations or have associated stigma or negative connotations and is 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). Recent studies have identified that Aboriginal 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 and Anangu Ngankari Tjutaku Aboriginal Corporation 2013). For these reasons, incorporation of Aboriginal traditional medicine and healing should be encouraged and supported, wherever practical.
References


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