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

SECOND EDITION

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

SECOND EDITION

Endorsed by

Australian Government
Cancer Australia

Cancer Council

Karabena Consulting

Statement of acknowledgement

Cancer Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of Country throughout Australia. We pay our respects to Elders, past and present. We celebrate the ongoing connections of Aboriginal and Torres Strait Islander peoples to Country, culture, community, family and tradition and recognise these as integral to health, healing and wellbeing. Cancer Australia acknowledges great diversity among Aboriginal and Torres Strait Islander peoples, and the contribution of the many voices, knowledge systems and experiences that guide all efforts to create a culturally safe and responsive cancer system that is equitable to all.

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

First published in August 2018. This edition published in October 2024.

ISBN: 978-1-7636672-1-1

© Cancer Australia 2024, *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer,* Second Edition, Cancer Australia, Surry Hills.

Enquiries about this publication can be sent to ocps@canceraustralia.gov.au

Copyright statement

This work is copyright. You may download, display, print and reproduce the whole or part of this work in unaltered form for your own personal use or, if you are part of an organisation, for internal use within your organisation, but only if you or your organisation do not use the reproduction for any commercial purpose and retain this copyright notice and all disclaimer notices as part of that reproduction. Apart from rights to use as permitted by the Copyright Act 1968 or allowed by this copyright notice, all other rights are reserved and you are not allowed to reproduce the whole or any part of this work in any way (electronic or otherwise) without first being given the specific written permission from Cancer Australia to do so. Requests and inquiries concerning reproduction and rights are to be sent to the Publications and Copyright contact officer, Cancer Australia,
Locked Bag 3, Strawberry Hills, NSW 2012.

Disclaimer

Cancer Australia does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information. Cancer Australia develops material based on the best available evidence; however it cannot guarantee and assumes no legal liability or responsibility for the currency or completeness of the information.

Contents

Welcome and introduction

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* has been revised to reflect current evidence and best practice and aims to reduce disparities and improve outcomes and experiences for Aboriginal and Torres Strait Islander people with cancer.

Cancer was the leading cause of death for Aboriginal and Torres Strait Islander people (AIHW, 2023a). Aboriginal and Torres Strait Islander people are more likely to be diagnosed with cancer, have poorer survival outcomes, and die from cancer when compared to non-Indigenous Australians. The gap in cancer outcomes between Aboriginal and Torres Strait Islander and non-Indigenous Australians is widening.

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

The distinct epidemiology of cancer among Aboriginal and Torres Strait Islander people, and unique connection to culture, highlight the need for an optimal care pathway for Aboriginal and Torres Strait Islander people with cancer. Ensuring this pathway is culturally safe and supportive is vital to addressing the disparities for Aboriginal and Torres Strait Islander people.

Optimal care pathways outline consistent, safe, high-quality and evidence-based care for people with cancer. Relevant to every step along the cancer continuum, the optimal care pathways aim to improve patient outcomes for people affected by cancer and ensure that Australians diagnosed with cancer receive the best care, irrespective of where they live or receive cancer treatment. The optimal care pathways have Australia-wide acceptance and government support.

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* has been designed to complement the cancer-specific optimal care pathways, focusing on the aspects of the care pathway that need to be responsive to the needs of Aboriginal and Torres Strait Islander people with cancer. The Second Edition has been led by an Aboriginal and Torres Strait Islander organisation, Karabena Consulting Trust, and refreshed through stakeholder consultation activities to ensure the updated optimal care pathway incorporates input from Aboriginal and Torres Strait Islander people, communities and healthcare providers.

In addition, Cancer Australia's Leadership Group on Aboriginal and Torres Strait Islander Cancer Control and Indigenous Advisors have provided significant strategic advice and input to the updated version. I sincerely thank them all for their generous contributions.

Optimal care pathways are endorsed by the Cancer and Population Screening (CAPS) Committee following advice from Cancer Australia's National Cancer Expert Group (NCEG). Formal endorsement by CAPS Committee acknowledges the importance of this optimal care pathway and the responsibility of the health system to deliver care in an appropriate, culturally safe, responsive and coordinated manner to ensure access and that optimal health outcomes are experienced by all Australians.

DMKeefe.

Professor Dorothy Keefe, PSM MD
CEO
Cancer Australia

Summary

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

The optimal care pathways describe the standard of care that should be available to all cancer patients treated in Australia. The pathways support patients and carers, health systems, health professionals and services, and encourage consistent optimal treatment and supportive care at each stage of a patient's journey. Seven key principles underpin the guidance provided in the optimal care pathways: patient-centred care; safe and quality care; multidisciplinary care; supportive care; care coordination; communication; and research and clinical trials.

This quick reference guide provides guidance to health practitioners and service planners on optimal care for Aboriginal and Torres Strait Islander people with cancer, across the cancer continuum. For Aboriginal and Torres Strait Islander people, health and connection to land, culture, community and identity are intrinsically linked. Health encompasses a whole-of-life view and includes a cyclical concept of life-death-life. Refer to the relevant cancer-specific optimal care pathway on the Cancer Council website www.cancer.org.au/OCP

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

Understanding your patient

- Understand the philosophies of holistic health and wellbeing and the role of Aboriginal and Torres Strait Islander knowledge, values, beliefs, cultural needs and health history in decision-making processes about treatment and ongoing care.
- Care coordination for each person should be informed by factors such as gender, kinship, family ties, language barriers and socioeconomic issues. Address issues including:
  - offer an option to see a health professional of the same gender as the patient, referral to an alternative culturally acceptable service provider if this is not possible, or the option of having a support person present for appointments or screening
  - privacy concerns of patient by reassuring that health professionals must abide by a privacy code of conduct
  - acknowledge that family may include people who are not genetically related.
- When discussing family history and genetic testing, understand that the concept of family is broader than being genetically related; discussing family members who are part of the Stolen Generation may be distressing.
- Be sensitive when discussing cultural taboos about cancer, Sorry Business (referring to people that have died), Men's and Women's Business and concerns about research exposure.
- Practise trauma-informed care and take steps to address intergenerational and contemporary trauma through culturally informed approaches.

Communication

- Support cross-cultural communication by asking the patient if they would like an Aboriginal and Torres Strait Islander Health Worker or Health Practitioner and/or other support person present during consultations and discussions
- Provide culturally specific and appropriate information that is accessible. Use culturally appropriate information resources and visual aids, including diagrams, images and videos.
- Use an interpreter if required.
- Avoid asking compound questions.
- Only use traditional terminology, such as referring to people as 'Aunty' or 'Uncle' if invited to do so.

Practical considerations for consultations

- Creating safe, welcoming and inclusive environments for Aboriginal and Torres Strait Islander patients.
- For rural and remote patients, consider home visits, telehealth and/or tele-oncology services where possible.
- Allow time to build rapport and trust with patients, while also ensuring timeframes meet evidence-based guidelines.
- Encourage and include family and/or community members/Elders/support people at appointments, if preferred.
- Ask if the individual identifies as Aboriginal and/or Torres Strait Islander and record this if a person wishes to identify as such.
- Ask permission before touching a patient and explain the reasons why it is necessary to touch them.
- Ensure the multidisciplinary team includes an expert in providing culturally appropriate care to Aboriginal and Torres Strait Islander people.

Please note that not all patients will follow every step of the pathway.

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

Step 1: Prevention and early detection

Risk reduction: Encourage Aboriginal and Torres Strait Islander people to:

- quit smoking
- maintain a healthy body weight
- be physically active
- avoid or limit alcohol intake
- eat a healthy diet
- reduce ultraviolet exposure
- complete immunisation schedule for hepatitis B and human papillomavirus (HPV)
- consider risk-reducing surgery or medication for people with a high hereditary or genetic risk of certain cancers.

Screening: Work closely with Aboriginal Community Controlled Health Services (ACCHS) to:

- encourage screening for colorectal, breast, cervical and lung cancer (National Lung Cancer Screening Program planned for July 2025)
- encourage discussion of prevention and early detection, and assess cancer risk at regular Medicare health assessments (including the Medicare Benefits Schedule (MBS) item 715 health assessment)
- address privacy concerns by building trust, emphasise confidentiality, offer alternate screening locations and promote self-screening.

- **Early detection:** Timely diagnosis can be enabled by:
- sharing knowledge about cancer, its symptoms and survivability
- discussions addressing concerns or fears
- increasing awareness of, and access to, affordable, convenient quality health services in remote and regional areas
- considering comorbidities masking cancer symptoms.

Step 2: Presentation, initial investigations and referral

Presentation: Some Aboriginal and Torres Strait Islander people may:

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

Referral: If diagnosis of cancer is confirmed or results are inconsistent, referral to an appropriate specialist is warranted.

- Ensure contact details are up to date to enable follow-up, and Aboriginal and/or Torres Strait Islander status is recorded (with consent).
- Provide culturally appropriate and accessible information about steps involved in investigation, and share with family and supports
- Connect patient with a culturally appropriate healthcare professional to facilitate attendance and communication at appointments.

Timeframes

Timely follow-up regarding status of referral is essential. Communication technologies, including telehealth, and additional discussions may facilitate the involvement of family members and carers in decision making within optimal care timelines.

Support and communication – lead clinician[1] to:

- ask whether the patient wishes a support person to be present during discussions
- routinely assess the supportive care needs of the patient and their families, ideally through using the Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP), repeating assessments as required
- provide the patient with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for appointments
- provide information about local support services
- support the patient while waiting for the specialist appointment. Local health professionals and/or Cancer Council nurses can provide information and reassurance via the national 13 11 20 information and support service. Health professionals can also access this service.

---

[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 3: Diagnosis, staging and treatment planning

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

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

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

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

Support and communication – lead clinician to:

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

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

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

Step 4: Treatment

Treatment intent: Establish and document if treatment:

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

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

Treatment options: Aboriginal and Torres Strait Islander people's perception and view of health, illness and treatment may impact on decision making.

When discussing treatment options with the patient, carer(s)/family supports, lead clinician to consider:

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

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

- offering the option for patients to discuss pain management with a health professional of the same gender
- offering oral pain relief options where appropriate
- using a pain tool that is culturally appropriate for the local community
- fully explaining options, usage and side effects of pain relief
- the effects of intergenerational trauma and the psycho-social aspects of pain that often exacerbate perceived pain and have impacts on pain management.

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

Place of care: For Aboriginal and Torres Strait Islander people living in regional and remote areas, the prospect of travelling to major cities for treatment can influence decision making regarding treatment.

Support and communication – lead clinician to:

- discuss treatment options with the patient/carer(s)/family support person, including the intent of treatment and expected outcomes
- discuss advance care planning with the patient/carer(s)/family support person where appropriate
- discuss the treatment plan with the patient's general practitioner or primary care provider
- discuss and document the patient's use (or intended use) of traditional or complementary or alternative medicine therapies.

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

Step 5: Care after initial treatment and recovery

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

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

- engaging Aboriginal and/or Torres Strait Islander Health Workers, Health Practitioners, the Primary Healthcare Coordinator and/or Hospital Liaison Officer to support the patient
- discussing the patient's beliefs and definition of living well to ensure health services are working towards the patient's ideal outcome
- offering referral pathways to social and emotional wellbeing services and mental health services
- Tele-oncology and telehealth appointments and/or mobile clinics, including those supported by local ACCHS, should be used where possible.

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

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

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

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

Support and communication – lead clinician to:

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

Step 6: Managing recurrent, residual or metastatic disease

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

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

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

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

Support and communication – lead clinician to:

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

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

Step 7: End-of-life care

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

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

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

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

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

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

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

Voluntary assisted dying: As voluntary assisted dying is legislated by state and territory governments, it is essential to know the law and rules around this choice in the state or territory where the patient lives (Cancer Council 2020).

Support and communication – lead clinician to:

- be open to, and encourage discussion about, the expected disease course while considering the patient's personal and cultural beliefs and expectations
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment
- ensure the family and carers understand and have written or other accessible-format information about the supportive care and pain management plans.

Context

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 leading cause of death for Aboriginal and Torres Strait Islander people and the gap in cancer mortality between Aboriginal and Torres Strait Islander and non-Indigenous Australians is widening (AIHW & NIAA 2023a). Compared to non-Indigenous Australians, Aboriginal and Torres Strait Islander people:

- are more likely to be diagnosed with cancer,
- more likely to die from cancer; from 2010–2019, the age-standardised death rate due to cancer increased by 12% for Indigenous Australians, while the rate for non-Indigenous Australians declined by 10% (AIHW & NIAA 2023a)
- have a lower 5-year relative survival; in 2014–2018, the five-year survival rate for all cancers was lower for both Aboriginal males (44%) and females (52%) than non-Aboriginal males (58%) and females (63%)(AIHW 2021; AIHW & NIAA 2023a)
- have higher levels of modifiable risk factors relevant to cancer (AIHW 2021; AIHW & NIAA 2023a; Li et al. 2018).

Many factors contribute to this gap, including social disadvantage (such as lower levels of education, employment and income and food insecurity), higher prevalence of cancer-related risk factors (such as high smoking rates, poor nutrition and physical inactivity) and poorer access to health services (AIHW 2021; NCCI 2022; AIHW & NIAA 2023b and 2023c). System-level barriers exist for Aboriginal and Torres Strait Islander people, including limited access to culturally safe services, systemic racism, discrimination, and social factors such as income inequality (Cancer Australia 2023).

Aboriginal and Torres Strait Islander people live in all parts of Australia, from urban to regional, remote and very remote areas. Aboriginal and Torres Strait Islander people are more likely to live in urban and regional areas than remote areas, although the proportion of the total population who are Aboriginal and Torres Strait Islander is generally higher in more remote areas (AIHW 2023a). People living in remote areas may have poorer access to care and are less likely to participate in Australia's national population screening programs, such as the BreastScreen Australia Program (DoHACa), the National Cervical Screening Program (DoHACb) and the National Bowel Cancer Screening Program (DoHACc; AIHW 2024).

While the clinical aspects of optimal care are the same for all people, irrespective of cultural heritage, optimal care should deliver health services that are determined to be culturally safe, trauma-informed, and with demonstrated responsiveness by the recipient of care, and not defined by the caregiver. The distinct epidemiology of cancer among Aboriginal and Torres Strait Islander people and a unique cultural connection to land and community highlight the need for an optimal care pathway for Aboriginal and Torres Strait Islander people with cancer.

National action

The National Agreement on Closing the Gap (National Agreement) (Coalition of Aboriginal and Torres Strait Islander Peak Organisations and Australian Governments 2020) provides an overarching context for closing Aboriginal and Torres Strait Islander inequity gaps in many areas of life. The target to close the life expectancy gap between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians by 2031 cannot be achieved without closing the cancer gap.

The Australian Cancer Plan (Cancer Australia 2023) and the Aboriginal and Torres Strait Islander Cancer Plan (NACCHO 2023) aim to deliver positive outcomes in the prevention, diagnosis and treatment of cancer in Aboriginal and Torres Strait Islander people. National actions include:

building the capacity and capability of ACCHS to support Aboriginal and Torres Strait Islander people with cancer.

strengthening specialist and targeted services to be culturally responsive and to reform mainstream health programs in collaboration with the Aboriginal Community Controlled Health sector (Cancer Australia 2023).

Intent of the optimal care pathways

The purpose of the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* is to complement the best practice information provided in cancer-specific optimal care pathways to facilitate the delivery of culturally safe and competent care.

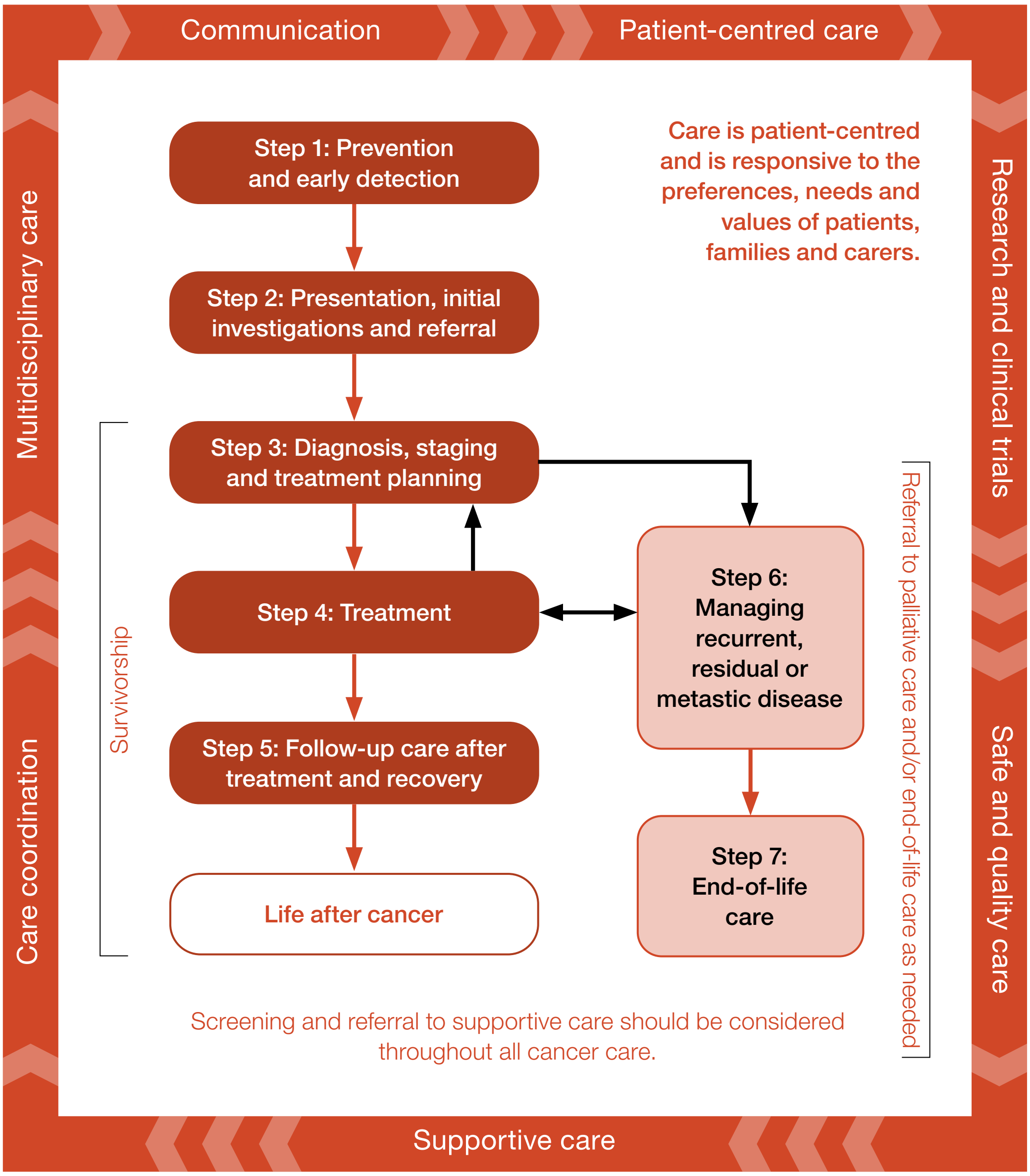
The optimal care pathways map seven key steps in cancer care. Each of these steps outlines nationally agreed best practice for the best level of care. While the seven steps appear in a linear model, in practice, patient care does not always occur in this way as it is dependent on the individual's situation (e.g. the type of cancer, when and how the cancer is diagnosed, prognosis, management, the patient's decisions and their physiological response to treatment) (Figure 1).

The principles underpinning optimal care pathways always put patients at the centre of care throughout their experience and prompt the healthcare system to deliver coordinated care. The optimal care pathways do not constitute medical advice or replace clinical judgement, and they refer to clinical guidelines and other resources where appropriate.

For health services to be effective for Aboriginal and Torres Strait Islander health care, they must operate in ways that show both understanding of, and respect for, the diversity in Aboriginal and Torres Strait Islander cultures. Therefore, this document focuses on the aspects of the cancer care pathway that need to be responsive to the needs of Aboriginal and Torres Strait Islander people with cancer.

Health services and health professionals can use this optimal care pathway as a tool to identify gaps in current cancer services and to inform quality improvement initiatives across all aspects of the care pathway. Clinicians can also use this optimal care pathway as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

Figure 1: The optimal care pathway



Optimal care pathway resources

There are three types of resources for each pathway: an optimal care pathway, a quick reference guide for health professionals, and guides to best cancer care for patients, carers, families and other support persons.

Optimal care pathways

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

SECOND EDITION

This optimal care pathway is designed for **health professionals and health services**. However, **patients and carers** may find useful information in this version to help understand the processes their treating health professionals are following. This resource aims to:

- assist health professionals to provide optimal care and support to patients with cancer, their families and carers
- provide optimal timeframes for delivering evidence-based care
- emphasise the importance of communication and collaboration between health providers and people affected by cancer
- assist and inform new health professionals or trainees who are entering the cancer care workforce
- provide value to health systems to identify gaps in current cancer services, bring about quality improvement initiatives and improve how services are planned and coordinated. Adherence to the pathways should be measured wherever possible.

Visit the Cancer Council website, www.cancer.org.au/OCP to view the optimal care pathways.

Quick reference guides

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

Quick reference guide

SECOND EDITION

The quick reference guides are for health professionals and health services. They provide a summary of each optimal care pathway.

The quick reference guides include:

- optimal timeframes within which tests or procedures should be completed
- checklists with indicators related to recommendations in the optimal care pathway.

Visit the Cancer Council website, www.cancer.org.au/OCP to view the quick reference guide for this optimal care pathway.

Guides to best cancer care

The guides to best cancer care are **consumer** resources that help patients understand the optimal cancer care that should be provided at each step. Carers, family and friends may also find the guides helpful.

The guides to best cancer care:

- include optimal timeframes within which tests or procedure should be completed include prompt questions to support patients to understand what might happen at each step of their cancer journey and to consider what questions to ask
- provide information to help patients and carers communicate with health professionals
- are available in eight languages.

Visit the Cancer Council's website, www.cancercareguides.org.au to view the guides to best cancer care.

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

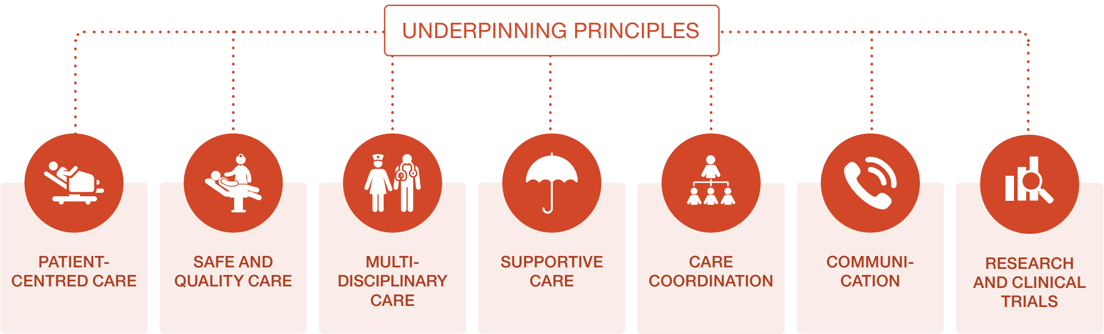
The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* provides a tool to help reduce disparities and improve outcomes and experiences for Aboriginal and Torres Strait Islander people with cancer. This resource can be used in conjunction with the optimal care pathway for each cancer type.

Visit the Cancer Australia website to view, www.cancer.org.au/OCP the optimal care pathway for Aboriginal and Torres Strait Islander people.

Principles of the optimal care pathway

The seven principles of care define appropriate and supportive cancer care that is the right of all Aboriginal and Torres Strait Islander people with cancer and those caring for them and their community.

Figure 2: The seven principles underpinning the optimal care pathway



The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* follows seven principles (Figure 2):

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

Each of the seven principles of the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* are underpinned by the evidence-based principles and key concepts set out in the *National Aboriginal and Torres Strait Islander Cancer Framework* (Cancer Australia 2015), including:

- 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 are 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 determinants and cultural determinants of health (Cancer Australia 2015).

Cutting across these principles is the promotion of Aboriginal and Torres Strait Islander self-determination and cultural expression throughout the cancer care journey, in alignment with collective human rights as Indigenous peoples (Australian Human Rights Commission). For Aboriginal and Torres Strait Islander people, health and connection to land, culture, community and identity are intrinsically linked. Health encompasses a whole-of-life view and includes a cyclical concept of life-death-life (Cancer Australia 2023). The connection of Aboriginal and Torres Strait Islander people to Country – traditional land and waters – is fundamental to cultural expression and must be respected across the cancer pathway.

For Aboriginal and Torres Strait Islander people, cultural safety is determined by Aboriginal and Torres Strait Islander individuals, families and communities. It cannot be determined by other stakeholders (NACCHO 2023). All patients must be asked whether they identify as Aboriginal and/or Torres Strait Islander, and their response clearly documented in their records. Ensuring cultural safety includes no challenge or denial of a person's identity (Williams 1999). Patients may not wish to identify themselves an Aboriginal and/or Torres Strait Islander, which must be respected (NSQHS 2020; AIHW).

Co-design is a critical methodology for realising Aboriginal and Torres Strait Islander self-determination (Butler et al. 2022b). The key principles and best practices for co-design in health with First Nations Australians (Anderson et al. 2023) encompass:

- First Nations leadership
- culturally grounded approach
- respect
- benefit to community
- inclusive partnerships
- transparency and evaluation.

Through the adoption of co-design approaches, Aboriginal and Torres Islander people will have a genuine say in the design and delivery of policies, programs and services that affect them, to achieve better life outcomes.

In practice, this means including the leadership of ACCHS and the communities they represent in co-designing optimal cancer services, programs and pathways (Durey et al. 2016), co-evaluation and reporting. Inviting and including Aboriginal and Torres Strait Islander community leadership in service and program governance mechanisms provides important support to ensuring the integrity of co-design processes and sustaining outcomes over time. More broadly, services and programs should routinely look to the leadership and seek direction of Aboriginal and Torres Strait Islander communities about the health service environments and care they provide. See Appendix A: Case study examples, The Beautiful Shawl Project.

Co-design is an important aspect of patient-centred care. Aboriginal and Torres Strait Islander patients, their families and carers should be supported to co-design optimal treatment and supportive care pathways for their circumstances (Anderson et al. 2023).

Principle 1: Patient-centred care

Patient-centred care is health care that is respectful of, and responsive to, the preferences, needs and values of the individual (ACSQH 2024). For Aboriginal and Torres Strait Islander peoples, optimal patient-centred care includes acknowledging the philosophies of holistic health and wellbeing, combined with the role of Aboriginal and Torres Strait Islander knowledge, values, beliefs, cultural needs, and health history in decisions about treatment and ongoing care. Culturally accepted patient-centred care also considers the impact of family structures and responsibilities, including kinship (COAG 2016).

For Aboriginal and Torres Strait Islander people health means not just the physical wellbeing of an individual, but refers to the social, emotional, cultural, spiritual and psychological wellbeing of the whole community. This means an individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life (NACCHO 2022).

Seven domains of Aboriginal and Torres Strait Islander social and emotional wellbeing have been identified (Commonwealth of Australia 2017) as:

- physical health
- mental and emotional health
- connection to family and kin
- connection to community
- connection to culture
- connection to Country (land and waters)
- connection to spiritual beliefs and practices.

In practising patient-centred care, the impacts of intergenerational trauma for Aboriginal and Torres Strait Islander people must be acknowledged and addressed. Health services and programs should practise trauma-informed care, understanding that trauma can influence the way people approach the health system and that the biological impact of stress and trauma can be an underlying cause of poor health. Refer to Principle 2: Safe and quality care for more information about trauma-informed health care and healing-informed care.

Cultural safety

Cultural safety is about *how* care is provided, rather than *what* care is provided, and identifies that health consumers are safest when clinicians have considered power relations, cultural differences and patients' rights (COAG 2016; APHRA 2020). It recognises the importance of self-determined decision making, partnership and collaboration in health care, which is driven by the individual, family and community (AHPRA 2020).

Culturally safe practice is the ongoing critical reflection of a health practitioner's knowledge, skills, attitudes, practising behaviours and power differentials, in delivering safe, accessible and responsive health care free of racism (APHRA 2020). It represents an ongoing educational journey, essential for unlearning biases and appreciating Aboriginal and Torres Strait Islander values (COAG 2016). Refer to Principle 2: Safe and quality care for more information about culturally safe and responsive practice.

Family, carer and community inclusive

For Aboriginal and Torres Strait Islander people, patient-centred care encompasses the individual, their family, carers and supports, and their identified community. It is respectful and accommodating of culturally shaped family structures, kinship and community across the care pathway (COAG 2016), and acknowledges that the concept of family may include people who are not genetically related (Ristevski et al. 2020).

As per the individual's preferences, family and carers should be supported at all stages of the cancer journey to:

- maintain connections with the patient
- participate in discussions, consultations and shared decision making, as genuine partners in the co-design of care
- have their own supportive care needs considered, managed and respected.

Refer to Principle 4: Supportive care for more information about family, care and community support.

Place-based care approach

Place-based approaches target the specific circumstances of an identified place, and engage with local people for the development and implementation of programs, services or policies that will have the greatest impact in identifying and responding to the unique needs of the local community. Place-based approaches are characterised by collaboration, partnership, co-design and a shared accountability with community. Place-based engagements will enable self-determination, empower Aboriginal and Torres Strait Islander voices and promote community-led decision making on cancer care priorities (Cancer Australia 2023). Where this occurs effectively, it underpins the concept of holistic care, as well as promoting optimal health outcomes for Aboriginal and Torres Strait Islander people.

Further information:

Refer to:

- Australian Health Practitioner Regulation Agency (AHPRA) Cultural Safety Strategy 2020–2025. www.ahpra.gov.au/About-Ahpra/Aboriginal-and-Torres-Strait-Islander-Health-Strategy/health-and-cultural-safety-strategy.aspx#
- Australian Health Ministers' Advisory Council Cultural Respect Framework 2016–2026 www.apo.org.au/sites/default/files/resource-files/2016-01/apo-nid256721.pdf
- AIHW 2023c. Cultural safety in health care for Indigenous Australians: monitoring framework www.aihw.gov.au/reports/indigenous-australians/cultural-safety-health-care-framework/contents/about.
- National Health Leadership Forum – Leading Aboriginal and Torres Strait Islander healthcare nhlf.org.au
- Australian Public Service Commission 2019. Aboriginal and Torres Strait Islander Cultural Capability Framework. www.apsc.gov.au/working-aps/diversity-and-inclusion/aboriginal-and-torres-strait-islander-workforce/cultural-capability-framework

Principle 2: Safe and quality care

Health services and health professionals are responsible for providing 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.

Culturally safe and responsive practice

Having a culturally safe and responsive workforce is a key strategy for reducing inequalities in healthcare (AIHW & NIAA 2023e). Developing and embedding cultural competence in health services requires a sustained focus on knowledge, awareness, behaviour, skills and attitudes at all levels of service, including at the operational or administrative service level, health practitioner level, practitioner–patient level and student-training level (Bainbridge et al. 2015; Cancer Australia 2015).

It is important to educate health professionals about institutional racism and unconscious bias because it may embed discrimination into the operations of health systems (AHMAC 2016). 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, as well as the institutional level, through built-in operations and systems; there is an opportunity to improve health outcomes for Aboriginal and Torres Strait Islander people by addressing this at both the individual and system levels (COAG 2016).

Cultural competence and cultural safety are not interchangeable terms (NACCHO 2023), rather, cultural competence is part of the continuum from being culturally aware to delivering culturally safe care (NATSIHWA 2017). As such, cultural training is not an endpoint. It rests with all staff delivering health care to improve their cultural competency individually and collectively as they work with Aboriginal and Torres Strait Islander patients, their family and carers and communities. It is important to continue to learn from community what culturally safe and responsive practice means for individuals within across the spectrum of healthcare intervention.

Actions that enable culturally safe and responsive practice may include:

- engagement with Aboriginal and Torres Strait Islander services and programs, including building sustainable relationships between mainstream and community-controlled health services
- ongoing cultural training and professional development, including programs co-designed by Aboriginal and Torres Strait Islander community (NACCHO 2023)
- continuous quality improvement, informed by feedback, and received from Aboriginal and Torres Strait Islander service users and healthcare professionals
- Early engagement of Aboriginal and Torres Strait Islander Health Workers and Health Practitioners, interpreters and other staff and community that deliver culturally safe care without increasing the concept of ‘cultural load’. Cultural load further adds to the concept of racism in the healthcare system, whereby health professionals that identify as Aboriginal and/or Torres Strait Islander are deemed ‘experts’ in health care for all Aboriginal and Torres Strait Islander people, without acknowledging that it is the responsibility of every health professional to adopt the concepts of cultural safety for everyone.

Implementation support checklist – Cultural competence

A health service must have strategies to improve the cultural safety and cultural competency of its workforce to meet the needs of Aboriginal and Torres Strait Islander patients for accreditation by the National Safety and Quality Health Service Standards.

Cancer Australia's Guide to Implementing the Optimal care pathway for Aboriginal and Torres Strait Islander People with Cancer includes the following service checklist.

Does your service:

- include cultural safety as a standing item within service governance?
- provide cultural safety protocols and pathways to all staff, including new staff, locums and Visiting Medical Officers?
- require all health service staff to undertake cultural competency training?
- involve ACCHS and the communities they represent in co-designing localised cultural competence training, accounting for communities' demographics, history, diversity, needs and aspirations?
- have established means to get input from people with expertise in caring for Aboriginal and Torres Strait Islander people?
- routinely seek and act on feedback from Aboriginal and Torres Strait Islander people on their experience?

(Cancer Australia 2020)

Further information

- Supporting the cultural competence of service and program staff is Priority One of the www.canceraustralia.gov.au/sites/default/files/publications/optimal-care-pathway-aboriginal-and-torres-strait-islander-people-cancer-guide/pdf/optimal_care_pathway_for_aboriginal_and_torres_strait_islander_people_with_cancer_the_guide.pdf.
- Refer to the Cultural Respect Framework 2016–2026 for Aboriginal and Torres Strait Islander Health www.healthinfonet.ecu.edu.au/key-resources/policies-and-strategies/32498/?title=Cultural+Respect+Framework+2016+2026+for+Aboriginal+and+Torres+Strait+Islander+health&contentid=32498_1
- The Australian Commission on Safety and Quality in Health Care publishes a National Safety and Quality Health Service Standards User Guide for Aboriginal and Torres Strait Islander Health. Action 1.21 provides a guide to Improving Cultural Competency www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-User-Guide-for-Aboriginal-and-Torres-Strait-Islander-Health.pdf
- National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031 www.health.gov.au/resources/publications/national-aboriginal-and-torres-strait-islander-health-workforce-strategic-framework-and-implementation-plan-2021-2031?language=en

Trauma-aware, healing-informed

All cancer care professionals working with Aboriginal and Torres Strait Islander people should understand trauma-informed care, accepted healing care, and be considerate of the unique experiences of Aboriginal and Torres Strait Islander people and the impacts of intergenerational trauma arising from past policies (Cancer Australia 2023).

The trauma of historical events, including those associated with colonisation, can pass on through generations (intergenerational trauma). In addition, some people directly experience trauma through exposure to an accident, family violence and abuse (HealthInfoNet 2024., Nasir et al. 2021; Atkinson 2013). Higher levels of trauma are reported in the Aboriginal and Torres Strait Islander population when compared to non-Indigenous Australians (Nasir et al. 2021).

Steps should be taken to address intergenerational and contemporary trauma through culturally informed approaches. These approaches must recognise the unique history across communities and cultures and that the impact of trauma will be different depending on this history (Department of Health 2017).

Trauma-informed care and healing-informed care extends to recognising and meeting the needs of the whole Aboriginal and Torres Strait Islander person; this is their family, carers and supports. In addition, there is the consideration of the potential vicarious trauma experienced by staff, in particular for the Aboriginal and Torres Strait Islander staff that are involved in an individual's care (Cubillo 2021).

Further information

- For more information about the principles of a trauma-aware, healing-informed approach, refer to Health*Info*Net: www.healthinfonet.ecu.edu.au/learn/health-topics/healing/trauma/

Data-driven quality care

Collecting and analysing data relevant to cancer care for Aboriginal and Torres Strait Islander people is necessary to inform evidence-based high-quality care. Included is the importance of establishing Aboriginal and Torres Strait Islander-led initiatives, which strengthen Indigenous Data Sovereignty and governance of cancer data.

All patients should be asked whether they identify as Aboriginal and/or Torres Strait Islander, and this should be clearly documented. Patients have the right to not identify themselves as Aboriginal and/or Torres Strait Islander at any time, which must be respected. It is also recognised that patients may choose later to identify as Aboriginal and/or Torres Strait Islander, which again is within their rights as a human being, when in a culturally safe space. 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.

Aboriginal and Torres Strait Islander patient experiences of health care should be reported through culturally appropriate patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) surveys (AIHWc 2023).

Applying co-design approaches in quality improvement processes is critical to ensuring Aboriginal and Torres Strait Islander measures of success are included in the assessment of services and programs (Bailie et al. 2016).

Implementation support strategy – Identification

- Review Action 5.8 of the National Safety and Quality Health Service Standards, which focuses on identifying people of Aboriginal and Torres Strait Islander origin: www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-User-Guide-for-Aboriginal-and-Torres-Strait-Islander-Health.pdf
- Establish systems for routine identification of people who identify as Aboriginal and/or Torres Strait Islander.

(Cancer Australia 2020)

Principle 3: Multidisciplinary care

Multidisciplinary care is an integrated team approach that involves all relevant health professionals discussing all relevant treatment options and making joint recommendations about treatment and supportive care plans, considering the personal preferences of patients.

Multidisciplinary care is considered the cornerstone of best practice cancer care and all patients should have the benefit of multidisciplinary treatment planning.

Specific multidisciplinary team (MDT) members will depend on the cancer type and are outlined in the cancer-specific optimal care pathways. Multidisciplinary care improves patient outcomes (Scott 2021). Cancer Australia's 'Principles of multidisciplinary care' provides a flexible definition, allowing services to vary implementation according to cancer type and the service location and context (Cancer Australia 2024a). The principles stipulate:

- a team approach that involves core disciplines that are integral to providing good care, including general practice and ACCHS, with input from other specialties as required
- communication among team members about treatment planning and follow-up plans
- access to the full therapeutic range for all patients, regardless of location (for Aboriginal and Torres Strait Islander people in regional and remote areas, this may be via referral)
- care delivery in accordance with nationally agreed standards
- patient involvement in decisions about their care.

Multidisciplinary meetings, often called MDMs, should be based on the principles outlined above.

Key components of multidisciplinary care for Aboriginal and Torres Strait Islander people include:

- essential involvement of a person experienced in providing culturally appropriate care to this population. This will preferably be an Aboriginal and/or Torres Strait Islander Health Worker or Health Practitioner, Aboriginal Hospital Liaison Officer, or Aboriginal and Torres Strait Islander staff member. Aboriginal and Torres Strait Islander patients should be given the choice of their involvement in the discussion. Studies consistently identify the value of Aboriginal and Torres Strait Islander staff being present and playing an active role at all steps of the cancer care pathway (Cramb et al. 2023; Green et al. 2021; Chynoweth et al. 2020; Sanjida et al. 2022; Ristevski et al. 2022; Olver et al. 2022; Anderson et al. 2021; Butler et al. 2023; De Witt et al. 2018; Hla et al. 2020; Christie et al. 2023a)
- consideration of the patient's kinship and family ties, as well as their personal, social and cultural circumstances, and factor all considerations into the person's treatment plan
- safe and effective cross-cultural communication among its members, including patients, their families and supports, and carers. Refer to Principle 6: Communication and Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer: further considerations: Cross-cultural communication for more information.

Further information

- For more information on the principles of multidisciplinary care and the benefits of adopting a multidisciplinary approach, see Cancer Australia's *Principles of multidisciplinary care* www.canceraustralia.gov.au/clinicians-hub/multidisciplinary-care/all-about-multidisciplinary-care/principles-multidisciplinary-care

Principle 4: Supportive care

Supportive care for patients, their families and carers is a vital part of any cancer treatment program. It is made up of all the services, information and resources they need to meet their physical, psychological, social, information, cultural and spiritual needs from the time of diagnosis.

Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes.

Supportive care may be 'patient-defined' and based on unmet needs. Supportive care is a standard or routine aspect of cancer care, and the treatment team should make patients aware of this.

Supportive care in cancer refers to the following five domains:

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

Aboriginal and Torres Strait Islander people with cancer often have more complex, distressing and broader needs than non-Indigenous Australians, including complexities associated with later-stage diagnosis (Lethborg et al. 2022) and comorbidities.

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

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

Supportive care should begin from the time of diagnosis and continue throughout the cancer pathway. The needs of Aboriginal and Torres Strait Islander people with cancer should be assessed using a culturally specific screening tool. Needs assessments should be conducted routinely and systematically across the cancer continuum, especially at transition points, as supportive care needs change (Valery et al. 2017. The needs of family and caregivers should also be assessed, so that those supporting Aboriginal and Torres Strait Islander patients through their cancer journey are also supported.

Validated screening

The Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) has been successfully used in diverse cancer care settings across Australia to assess the distinct and other support needs of Aboriginal and Torres Strait Islander people with cancer. It asks questions about needs in four domains (hospital care, information and communication, physical and psychological, and practical and cultural). The tool is delivered verbally to the patient and takes around 15 minutes to complete. Results can be quickly scanned to identify moderate to high-need items for prioritisation and follow-up.

The National Comprehensive Cancer Needs Distress Thermometer and Problem List provides a scale for the amount of concern or worry a patient may be experiencing. The Problem List helps identify the causes of these concerns or worries.

All members of the multidisciplinary team have a role in providing supportive care along the care pathway.

In addition, support from ACCHS and Aboriginal Community-Controlled Organisations, family, friends, Elders, community, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

Responding to support needs can involve connecting patients, their families and carers to:

- information about support services
- Aboriginal and Torres Strait Islander Health Workers and Health Practitioners, including ACCHS
- patient coordination and assistance services, such as:
  - Patient Assisted Travel Schemes regarding assistance with travel and accommodation costs when accessing treatment. These services vary by jurisdiction
  - the Aboriginal and Torres Strait Islander-specific Integrated Team Care program
- community support organisations including peer and other support groups (Butler et al. 2023; Meiklejohn et al. 2018)
- rehabilitation services (refer to Rehabilitation and recovery, section 5.4.2) (Bainbridge et al. 2015).

Supportive care for family and carers

Major causes of distress for a carer include (Cancer Australia 2018):

- the physical care demands of the person affected by cancer
- dealing with distressing symptoms, such as pain and/or disfigurement and disability
- uncertainty about the illness trajectory
- fluctuations in the individual's mental status, behaviour and/or personality
- feelings of guilt, unhappiness, depression and emotional upset, resulting in difficulty to remain 'positive'
- a perceived lack of information and capacity to undertake carer role, despite a need to do such
- changes in intimacy and relationship dynamics.

For carers, supportive care can also involve:

- facilitating access to medical supplies and resources needed for home-based and other ongoing patient care needs
- providing information and skills training, as required, for home-based care and other care responsibilities in different formats, like instructional videos and step-by-step information guides
- providing skills training and other support materials; for example, instruction for safe lifting techniques, wound care, administration of medications and/or feeds/fluids, as well as the operation of specialised equipment.

After referral to supportive care services and programs, ensuring patients, their families and carers are attending the recommended follow-up appointments with specialist care is important. The responsibility for this task should be clearly assigned to a member of the multidisciplinary care team who has a relationship with the patient and their nominated family members and their supports.

Key review points

The treatment team should assess the patient (and, where applicable, their family and carers/supports) for supportive care needs at these key stages:

- initial presentation or diagnosis
- beginning of treatment, a new phase of therapy or a new treatment modality
- significant change in prognosis
- patient is found to have an underlying germline genetic mutation predisposing to cancer
- end of treatment
- throughout survivorship as any new issues emerge
- following significant adverse events
- diagnosis of disease recurrence
- significant change in, or development of, new symptoms
- transition to end-of-life care, including a desire to be home on Country
- other time points based on clinical judgement.

Further Information

- Learn about the SCNAT-IP tool www.scnatip.org/
- Learn more about the Distress Thermometer and Problem List at the National Comprehensive Cancer Needs (NCCN) dedicated webpage (free registration required to access) www.nccn.org/professionals/physician_gls/pdf/distress.pdf
- Patient Assisted Travel Schemes and other organisations that support patient, family and carer travel and accommodation www.healthdirect.gov.au/travelling-to-your-healthcare-appointment#resources
- Information on the Integrated Team Care program www.health.gov.au/our-work/integrated-team-care-program
- An Evidence Check rapid review brokered by the Sax Institute for the Cancer Institute NSW. Evidence Check: Support along the cancer pathway for Aboriginal and Torres Strait Islander peoples www.saxinstitute.org.au/wp-content/uploads/22.05_Evidence-Check_Support-along-the-cancer-pathway-for-Aboriginal-People.pdf.

Principle 5: Care coordination

Care coordination is the responsibility of every professional, both clinical and non-clinical, who works with patients, their families and carers.

Seamless care coordination is essential for patients to successfully navigate the complex health system. Care coordination is a comprehensive approach to achieving continuity of care for patients. It aims to ensure care is delivered in a systematic, connected and timely way that promotes efficiency and reduces the risk of duplication and over-servicing to meet the medical and personal needs of patients.

Effective care coordination for Aboriginal and Torres Strait Islander people requires building relationships and trust, and ensuring the workforce is culturally safe and responsive (see Culturally safe and responsive practice in Principle 2). Gender, kinship and family ties, language barriers and socioeconomic issues should be addressed to provide individualised care coordination for all patients as a holistic approach to care.

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. For Aboriginal and Torres Strait Islander patients, care coordination may involve:

- Aboriginal and Torres Strait Islander Health Workers and/or Health Practitioners
- primary healthcare coordinators

- other care coordination or navigation programs (for example, the Integrated Team Care program which may involve a crossdisciplinary approach from medical/nursing/allied health/Indigenous health worker
- primary healthcare professional involved in ongoing treatment (e.g. general practitioner or nurse practitioner).

Care coordination encompasses multiple aspects of care delivery, including:

- multidisciplinary team meetings
- patient travel logistics
- supportive care screening/assessments and supportive care planning, including family and carer support
- navigation and referral systems
- comorbidities management
- information provision to the patient, their family and carers, confirming that it is understood by all parties involved
- patient informed consent, aligned with decision support, as required
- patient record and data collection
- development of common protocols, such as effective communication protocols that are culturally accepted and meet both patient and clinical needs.

Care coordination must include multidisciplinary teams effectively communicating and working with primary healthcare providers, including ACCHS. This needs to be evidenced through patients' outcomes statistics, as well as health workforce deliverables. In addition, it would be pertinent for Aboriginal and Torres Strait Islander health outcomes to measure the experience of individual cancer patients' carers and supports so to determine acceptance of cultural needs and efficacy in the delivery of safe and quality cancer care.

Within the primary healthcare sector, care coordination often involves broader coordination activities, including advocating on behalf of the patient, ensuring culturally safe and responsive services are received, supporting the patient to attend appointments, monitoring and encouraging completion of treatment, streamlining referral systems to specialists, providing health education as appropriate, and identifying when further assistance from a health professional is required. A culturally safe workforce is evidenced as key to quality patient-centred, culturally safe care (Cramb et al. 2023; Green et al. 2021).

Due to the high prevalence of comorbidities among Aboriginal and Torres Strait Islander populations, some Aboriginal and Torres Strait Islander people may have an established or ongoing relationship with a primary healthcare coordinator (under the Integrated Team Care program 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 primary care provider is an essential component of optimal care coordination and may involve:

- gathering information from the local ACCHS or primary care provider, including their perspective on the personal situation (psychological issues, cultural preferences, social issues and comorbidities), and other locally available support services
- timely communication of diagnostic information and treatment plan (within a week) and regular updates on the patient's progress, including changes in treatment or supportive care plans, or enrolment in research and clinical trials
- being involved in treatment and supportive care planning, and advocating to ensure patients receive culturally safe care and have cultural needs met
- discussing shared care arrangements, including contributing to a chronic disease and mental healthcare plan as required
- establishing the role of the primary care provider in symptom management, psychosocial care and referral to local services
- supporting service delivery of optimal care pathway and system navigation, inclusive of appointment attendance and follow-up, and notifying the primary care provider and their supports, such as Aboriginal and/or Torres Strait Islander Health Workers, Health Practitioners and/or Hospital Liaison Officers and family/carers, where the patient has difficulty in accessing follow-up appointments or managing the therapeutic determinants of their care.

Relationships with primary healthcare providers, including ACCHS, can be supported by interservice protocols, including for:

- interservice and other referrals
- record sharing with patient consent in line with continuity of care
- patient consent and collaboration to ensure communication is supported by Aboriginal and Torres Strait Islander Health Workers or Health Practitioners
- procedures to follow up an inability to meet scheduled appointments.

Particularly important is the timely handover of patient records from hospitals and services to primary healthcare services, including ACCHS, after cancer treatment. Responsible officers should be identified for this task.

Care coordination for Aboriginal and Torres Strait Islander people in regional and remote areas are supported by:

- partnerships between primary care providers. Importantly, identifying the patient's primary healthcare provider in their region may involve contacting the patient's local ACCHS. It is important to consider those areas with metropolitan health and cancer services, including specialists, which support place-based care and reduce travel demands on patients, their families and carers
- facilitating financial assistance to support patient travel as required, including the use of Patient Access Transport Schemes (that vary between states and territories) and Integrated Team Care programs aimed at improving chronic disease management
- telehealth to facilitate timely discussion and involvement of family members and carers in decision making within the optimal care timeline.

Further information

- Cancer Australia's Guide to Implementing the Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer includes:
  - Priority 2 – Integrating the planning and delivery of care across services
  - Priority 3 – Supporting culturally appropriate care coordination and support www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/guide-implementing-optimal-care-pathway-aboriginal-and-torres-strait-islander-people-cancer]
- Information on the Integrated Team Care program www.health.gov.au/our-work/integrated-team-care-program
- View the Interpretive guide to the Royal Australian College of General Practitioners (RACGP) Standards for general practices (4th edition) for Aboriginal Community Controlled Health Services https://www.racgp.org.au/running-a-practice/practice-standards/interpretive-guide-1/interpretative-guide-for-aboriginal-community-cont]
- For information on the different state and territory Patient Travel Assisted Schemes Fact Sheets | NRHA - National Rural Health Alliance
- For information about Aboriginal Community Controlled Health Services www.naccho.org.au/

Principle 6: Communication

Everyone employed in the healthcare system is responsible for ensuring the communication needs of patients, their families and carers are met.

Across all steps of the cancer care pathway, communication with Aboriginal and Torres Strait Islander patients, inclusive of families and carers (with consent), should be:

- respectful and trusted
- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally safe, e.g. that takes account of gender (Men's and Women's Business), family ties, language barriers and health literacy
- interactive, proactive and encourage questioning
- ongoing
- delivered in an appropriate setting and context.

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

Hearing impairment disproportionally affects Aboriginal and Torres Strait Islander people (AIHW 2023b). Consideration must be given to the impact on effective communication and potential for disengagement, and individualised communication strategies identified.

Culturally safe communication includes being sensitive about using traditional terminology such as referring to people as 'Aunty' or 'Uncle' without being invited to do so. Instead, seek guidance from the person introducing the Elder, or directly ask the Elder what they would prefer. 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.

Health professionals should note that when discussing death or dying with Aboriginal and Torres Strait Islander people, the terms 'passing', 'not going to get better' or 'returning to Country' may be more accepted due to spiritual beliefs around the life cycle. Obtain guidance about passing from the Aboriginal and/or Torres Strait Islander Health Worker, Hospital Liaison Officer or relevant identified health professional, and ensure patients understand their prognosis and treatment.

Strategies for supporting effective communication may include:

- identifying present and accessible Aboriginal and Torres Strait Islander staff (Cramb et al. 2023; Green et al. 2021; Chynoweth et al. 2020; Sanjida et al. 2022; Ristevski et al. 2022; Olver et al. 2022; Anderson et al. 2021; Butler et al. 2023; De Witt et al. 2018; Hla et al. 2020; Christie et al. 2023a), including interpreters
- providing recordings or summaries of key consultations to facilitate recall of information and treatment decisions
- with consideration to health literacy, offer the patient a Question Prompt List in advance of their consultation (Brandes et al. 2015) as appropriate, to facilitate discussion and shared decision making
- using technology to facilitate interactions, such as telehealth, as appropriate.

For further unique considerations, refer to section Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer: further considerations: Cross-cultural communication.

Further information

- Online training communication skills for non-Indigenous professionals www.canceraustralia.gov.au/culturally-safe-communication-skills-tips-for-non-Indigenous-health-professionals
- Cancer Institute NSW: Question prompt lists for people with cancer. These contain easy to refer to questions for people with cancer and their families. They are not Aboriginal and Torres Strait Islander-specific www.cancer.nsw.gov.au/about-cancer/document-library/question-prompt-lists-for-people-with-cancer-trans

Principle 7: Research and clinical trials

Research and clinical trials play an important role in establishing the efficacy and safety of diagnostic, prognostic and therapeutic interventions, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalcberg 2013).

Access to research and clinical trials provides patients an opportunity to receive the latest Treatment | Cancer Australia and the best possible care. At the cancer population level, clinical trial participation is positively associated with increased survival and decreased mortality, and greater participation can accelerate advances in treatment (Cunningham et al. 2021).

Aboriginal and Torres Strait Islander people do not access cancer research and clinical trials in an equitable way when compared to the non-Indigenous population. All patients should be considered and, where appropriate, offered the opportunity to participate in cancer research or clinical trials at any stage of the care pathway, while being reassured that opting not to participate in research will not affect the standard of care they receive (Cunningham et al. 2021).

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 (NHMRC 2018).

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

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 (Cunningham et al. 2021).

The use of telehealth improves equity of access to clinical trials and is recommended by national and international professional groups, such as Clinical Oncology Society of Australia and American Society of Clinical Oncology. Some components of a clinical trial, such as prescreening visits, mid-cycle visits, blood tests and scans can be delivered using telehealth in collaboration with local care providers to reduce travel to large metropolitan centres.

Further information

- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants http://www.australiancancertrials.gov.au/
- The National Health and Medical Research Council's Ethical guidelines for research with Aboriginal and Torres Strait Islander peoples www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-research-aboriginal-and-torres-strait-islander-peoples
- The Australian Teletrial Program aims to improve access to, and participation in, clinical trials for rural, regional and remote Australians www.australianteletrialprogram.com.au/
- Access to clinical trials closer to home using tele-health – A national guide for implementation www.cosa.org.au/media/332325/cosa-teletrial-model-final-19sep16.pdf and Telehealth in oncology: ASCO standards and practice recommendations: www.doi.org/10.1200/OP.21.004
- Aboriginal and Torres Strait Islander People with Cancer – Clinical trial access initiative www.menzies.edu.au/page/Resources/Aboriginal_and_Torres_Strait_Islander_People_with_Cancer_Clinical_Trial_Access_Initiative_Consultancy_Report_for_ReViTALISE_Project/

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

This section provides further information and guidance about unique concepts in Aboriginal and Torres Strait Islander cancer care, addressed 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 care pathway.

Healthcare environment

Optimal cancer care begins with creating a safe, welcoming and inclusive environment for all patients. For Aboriginal and Torres Strait Islander patients with cancer, healthcare environments that are effective contribute to cultural safety.

Hospitals may be considered a place of fear for some Aboriginal and Torres Strait Islander people. Creating safe, welcoming and inclusive environments for Aboriginal and Torres Strait Islander patients can be facilitated by:

- engaging with local Aboriginal and Torres Strait Islander people, communities and organisations to establish and maintain good working relationships. This includes seeking feedback on cultural inclusiveness and advising if any improvements can be made to the health service environment(s) across the entire health workforce and care continuum
- visible and prominent safety messaging: commitment to Reconciliation through an accessible action plan, promoting culture through displays of artwork and music (where applicable), and acknowledging and engaging the Traditional Owners of lands on which services are located to ensure co-design
- presence of, and access to, Aboriginal and Torres Strait Islander staff, including the development of an Aboriginal and Torres Strait Islander health workforce through mentoring, cadetships and sponsorship
- supporting the attendance of family, carers and support people, as decided by the patient, at appointments and patient visits
- where possible, providing outdoor spaces or gardens as patient and family areas, acknowledging that for some Aboriginal and Torres Strait Islander people outdoor spaces are regarded as culturally safer than institutional settings (Taylor et al. 2018; Anderson et al. 2021)
- accounting for Men's and Women's Business, for example, providing a separate women's or men's clinic, or entrance (Butler et al. 2020).

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

- asking if the patient would like to bring a support person to appointments or screening
- reassuring people during health information sessions and in printed resources that health professionals must abide by a privacy code of conduct, and that there is recourse if needed to present a complaint
- providing referrals to other health services that are culturally accepted by the individual, should they not be comfortable being seen at their local health service, or where their health needs are not met
- allowing flexibility with appointments to enable patients to be seen by preferred health professionals
- home visits, telehealth and/or tele-oncology services should be supported where possible (Zon et al. 2021; Mooi et al. 2012; Clinical Oncology Society of Australia 2015). Services and programs should partner with ACCHS and the communities they represent to co-design culturally safe healthcare environments.

Further information

- Telehealth in Oncology: ASCO Standards and Practice Recommendations www.ascopubs.org/doi/10.1200/OP.21.00438
- Teleoncology for Indigenous Patients: The Responses of Patients and Health Workers www.onlinelibrary.wiley.com/doi/10.1111/j.1440-1584.2012.01302.x
- Clinical Practice Guidelines for Teleoncology www.cancer.org.au/clinical-guidelines/teleoncology

Relationship building with the local community

Aboriginal and Torres Strait Islander people belong in all stages of service and program initiation, co-design governance and evaluation. Engaging and involving local Aboriginal and Torres Strait Islander communities early in both the planning and the delivery of health services and programs is an important way to acknowledge their place in these processes. This can also be facilitated by improving familiarity with local Aboriginal or Torres Strait Islander history, organisations (such as ACCHS 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 the Aboriginal and Torres Strait Islander community
- services and programs running open days and community events, including at hospitals, and inviting ACCHS and community members to attend. In turn, health services respectfully attending local Aboriginal community events so the community feel the health service is supporting them
- including Aboriginal and Torres Strait Islander communities as represented by their ACCHS in service and program governance (Cancer Australia 2020)
- providing outreach and mobile services and programs in community, or in collaboration with the ACCHS
- considering best practice cancer care for Aboriginal and Torres Strait Islander people through local consultation and advisement when developing and implementing practice and service guidelines.

When establishing relationships and consulting with your local Aboriginal and Torres Strait Islander communities in the co-design of services and programs, it is recommended to:

- contact local Aboriginal and Torres Strait Islander agencies, including ACCHS, 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
- attend meetings accompanied by an Aboriginal and Torres Strait Islander person
- consider cultural safety during all interactions, including involvement of Aboriginal and Torres Strait Islander facilitators and staff by leading with an Aboriginal and Torres Strait Islander advisor (preferably local, but may be state/nationwide)
- be prepared to remunerate community members for their time and for sharing their lived experience.

Building relationships and establishing trust takes time. In this context, it is important to commit to a broad and ongoing relationship building. Relationships should be reciprocal in nature.

Further information

- For further information about building effective and ongoing relationships with Aboriginal and Torres Strait Islander communities, organisations and groups that represent or service this population, refer to:
  - National Safety and Quality Health Service (NSQHS) Standards: User Guide for Aboriginal and Torres Strait Islander Health Action 2.13: Working in partnership www.safetyandquality.gov.au/standards/national-safety-and-quality-health-service-nsqhs-standards/resources-nsqhs-standards/user-guide-aboriginal-and-torres-strait-islander-health/action-213-working-partnership
- Australian Bureau of Statistics community profiles www.abs.gov.au/census/guide-census-data/about-census-tools/community-profiles. Community-level demographic data are published by the Australian Bureau of Statistics.

Cross-cultural communication

Cross-cultural communication ensures that, regardless of the cultural background or language of the patient, clinical information and options are understood, and the patient, their family and carers can make informed decisions. This section should be read in conjunction with Principle 6: 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 currently does not necessarily align with, and is not necessarily responsive to/or has not been responsive to, Aboriginal and Torres Strait Islander people and cultures (COAG 2016).

In the broader context, applying cross-cultural communication skills includes:

- making time to build rapport and trust and not ‘rushing’ patients to make uniformed decisions about their care and treatment
- considering that English may not be the patient’s first language and providing access to an interpreter, or other cultural supports that are meaningful to the patient
- supporting a yarning style of communication
- avoiding compound questions and instead asking single questions at a time
- appreciating potential differences in the use of non-verbal communication such as silence or, in some cases, a lack of direct eye contact
- respecting privacy by avoiding discussions in public areas or where the patient feels ‘unsafe’
- recognising that patients may feel discomfort, and in some circumstances shame, when sharing personal and private issues
- appreciating the concept of Men’s and Women’s Business (refer to Men’s and Women’s Business section below)

- being mindful of questions that can seem intrusive (for example, minimise confrontation by beginning with “Maybe this is a bit embarrassing to ask you about, but …”)
- avoiding using traditional terminology such as referring to people as ‘Aunty’ or ‘Uncle’ without being invited to do so
- asking permission before touching a patient and explaining the reasons why it is necessary to touch them.

Cross-cultural communication can be further supported by:

- asking the patient if they would like an Aboriginal and Torres Strait Islander Health Worker or Health Practitioner and/or other support person present during consultations and discussions
- having someone familiar and trusted by the patient facilitate introductions of unfamiliar staff
- including family and carers in discussions, with patient consent
- using culturally appropriate information resources and visual aids, including diagrams, images, videos
- offering advice on how to access information and support from websites, community and national cancer services and support groups, including resources and support groups for Aboriginal and Torres Strait Islander peoples, which may offer a safe alternative to those offered within mainstream services.

Further information

- The Australian Commission on Safety and Quality in Health Care has developed a ‘User Guide for Aboriginal and Torres Strait Islander Health’ to support health service organisations implement the six Aboriginal and Torres Strait Islander health-related actions in the National Safety and Quality Health Service (NSQHS) Standards www.safetyandquality.gov.au/standards/nsqhs-standards/resources-nsqhs-standards/user-guide-aboriginal-and-torres-strait-islander-health
- Further to the above, the Australian Commission on Safety and Quality in Health Care developed supplementary guides including Effective and Safe Communication with Aboriginal and Torres Strait Islander Consumers www.safetyandquality.gov.au/sites/default/files/migrated/05-Effective-and-safe-communication.docx
- Refer to the Cultural Respect Framework 2016–2026 www.nacchocommunique.files.wordpress.com/2016/12/cultural_respect_framework_1december2016_1.pdf
- Refer to Queensland Health’s Communicating effectively with Aboriginal and Torres Strait Islander people www.health.qld.gov.au/__data/assets/pdf_file/0021/151923/communicating.pdf

Men’s and Women’s Business

Men’s and Women’s Business is fundamental to many Aboriginal and Torres Strait Islander cultures. Respecting Men’s and Women’s Business is critical to cultural safety and can have influence on consultations, uptake of screening and participation in treatment.

Where possible, it is suggested that services are provided by a health professional of the same gender as the patient. Guidance regarding preferences should be sought directly from patients, rather than assumed.

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

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

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

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

Health literacy

Higher levels of health literacy 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 health knowledge and/or fear about cancer as a ‘death sentence’, including fear of the signs and symptoms of cancer, resulting in avoidance of ‘help-seeking’ (Meiklejohn et al. 2019; Butler et al. 2022a)
- fear of the mainstream medical system, including an association of dying where one attends hospitals (Meiklejohn et al. 2019; Butler et al. 2022a), 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’, and accompanied by shame (Treloar et al. 2013; Olver et al. 2022)

limited understanding about genetic testing and genomics in cancer
(see Genetic counselling and testing, section 1.2.5).

Community-based cancer education led by ACCHS is effective in supporting health literacy and is associated with an increased uptake of screening, earlier presentation, diagnosis and treatment (Meiklejohn et al. 2019). Strategies to promote health literacy and improve perceptions of mainstream healthcare include:

- effective cross-cultural communication skills that encourage questions, including from family and carers (refer to section Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer: further considerations: Cross-cultural communication for example using yarning methodologies (Shay 2021)
- respecting Men’s and Women’s Business in this context
- engaging cancer survivors or people affected by cancer to share their experiences, to promote screening, reduce the stigma of seeking treatment and to share stories about survival (Meiklejohn et al. 2018; Meiklejohn et al. 2019; Taylor et al. 2018; Taylor et al. 2021)
- providing or connecting people to resources that are culturally appropriate; for example, screening information during regular primary care provider appointments, consumer guides at the time of diagnosis, supportive resources explaining genetic testing
- creating video tours of facilities to use as a patient education tool.

Culturally appropriate resources

Using culturally-specific and appropriate information in formats that are accessible to Aboriginal and Torres Strait Islander people can greatly enhance the quality of care and patient experiences.

Resources developed by ACCHS and co-designed with local communities, are reported to be more appropriate and useful than educational materials that were created by external organisations (Taylor et al. 2021). Materials should be produced in Aboriginal and Torres Strait Islander languages (Tapia et al. 2019).

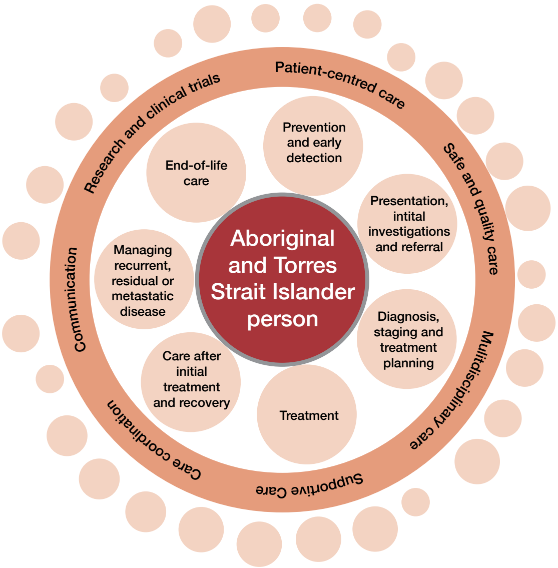
Key health professionals involved in patient care should routinely consider a patient's need for additional information and supply resources or contact information for appropriate services, as needed. Appropriate formats may include phone helplines, webpages and brochures.

Further information

- Our Mob and Cancer website. Developed for Aboriginal and Torres Strait Islander people for Aboriginal and Torres Strait Islander people, provides information about cancer, including cancer types, prevention, diagnosis, treatment, living with cancer, finding support and clinical trials www.ourmobandcancer.gov.au/
- Consumer guides:
  - Cancer – what to expect. Information for Aboriginal and Torres Strait Islander people who have cancer www.cancer.org.au/assets/pdf/cancer-what-to-expect
  - Checking for Cancer – what to expect. Information for Aboriginal and Torres Strait Islander people who have cancer www.cancer.org.au/assets/pdf/checking-for-cancer-what-to-expect-aboriginal-and-torres-strait-islander

Optimal care pathway

Figure 3: Patient-centred care for Aboriginal and Torres Strait Islander people



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

This optimal care pathway is intended to complement the cancer-specific optimal care pathways, 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 (Figure 3). 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: further considerations.

To view the full clinical optimal care pathway for each cancer type, visit www.cancer.org.au/OCP

Step 1: Prevention and early detection

This step outlines 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:

- higher levels of modifiable risk factors relevant to cancer, including smoking, alcohol consumption, low levels of physical activity (AIHW & NIAA 2023a)
- lower participation in cancer screening programs for breast, cervical and bowel cancer (AIHW & NIAA 2023c)
- a different pattern of cancer incidence, with some cancers occurring more frequently than among non-Indigenous people in Australia, including lung, liver, head and neck, uterine and cervical cancers (AIHW 2018), and a higher incidence of poor outcome, screen-detectable and preventable cancers, that are more likely to be diagnosed at more advanced stages, often with complex comorbidities, (AIHW & NIAA 2023a).

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

The item 715 Medicare Benefits Schedule (MBS) 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

- Refer to AIHW publications for current data on cancer epidemiology, including incidence, survival and mortality rates, in the Aboriginal and Torres Strait Islander population. This includes:
  - The Aboriginal and Torres Strait Islander Health Performance Framework (published with the National Indigenous Australians Agency), which includes a regularly update cancer-specific webpage www.indigenoushpf.gov.au/measures/1-08-cancer
  - Cancer in Australia, a national collation and analysis of cancer data, which includes a dedicated section on Aboriginal and Torres Strait Islander peoples (2021 edition) www.aihw.gov.au/getmedia/0ea708eb-dd6e-4499-9080-1cc7b5990e64/aihw-can 144.pdf?v=20230605165731&inline=true
- Refer to the National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people, developed by NACCHO and the RACGP www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/national-guide A fourth edition is due and is anticipated in 2024

- For MBS items, including the 715 Aboriginal and Torres Strait Islander health assessments, refer to:
  - Information on MBS item numbers to support preventive health assessments is available at MBS Online www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Home
  - Learn more about the MBS item 715 health assessment for Aboriginal and Torres Strait Islander people at the MBS Online-dedicated webpage www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=715
- Cancer Australia resources:
  - Our Mob and Cancer website, with information on cancer including cancer types, prevention, diagnosis, treatment, living with cancer, finding support and clinical trials: www.ourmobandcancer.gov.au/ways-to-help-protect-against-cancer
  - Yarn for Life, an internet resource with videos featuring Aboriginal and Torres Strait Islander people sharing their cancer journeys. It aims to support Aboriginal and Torres Strait Islander people to talk about cancer and seek help if required www.yarnforlife.com.au/

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.

The Aboriginal and Torres Strait Islander population have higher exposure to modifiable cancer risk factors (AIHW & NIAA 2023a), including:

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

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

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

The joint effect of 19 selected behavioural, metabolic, environmental and dietary risk factors were found to have contributed 56% of the burden for cancer for Aboriginal Australians in 2018, the biggest contributors being tobacco use (37%) and alcohol use (9.2%) (AIHW & NIAA 2023a).

Diabetes is an established risk factor for some cancers and is found in the Aboriginal and, in particular, the Torres Strait Islander populations at significantly higher rates than among the non-Indigenous population (Li et al, 2018; Sargis et al. 2019; Giovannucci et al. 2010; AIHW & NIAA 2023d).

1.2 Risk reduction

All patients should be aware of and encouraged to optimise their modifiable risk factors (see Risk factors, section 1.1).

The World Health Organization estimates that between 30% and 50% of cancers can be prevented by avoiding risk factors and implementing existing evidence-based prevention strategies (WHO 2024). The joint effect of behavioural, metabolic, environmental and dietary risk factors are estimated to contribute to over half the burden for cancer for Aboriginal and Torres Strait Islander peoples (AIHW & NIAA 2023a).

Aboriginal and Torres Strait Islander people who are in regular contact with primary health services have better cancer outcomes (Banham et al. 2023). Health professionals are in an ideal position to promote and advise on risk reduction strategies relevant to Aboriginal and Torres Strait Islander people that account for social, cultural and other factors. The MBS item 715 health assessment for Aboriginal and Torres Strait Islander people should be used routinely to identify risk factors and strategies to reduce risk of cancer.

Non-Indigenous health professionals should be led and directed by ACCHW, Aboriginal and Torres Strait Islander Health Workers and Practitioners and other Aboriginal and Torres Strait Islander staff regarding how best to provide advice. They should aim to understand the personal, family and community contexts of Aboriginal and Torres Strait Islander patients and communicate in a culturally competent way that avoids shaming.

1.2.1 Cancer risk reduction

General risk reduction advice includes:

- quitting smoking
- maintaining a healthy body weight
- being physically active, which offers benefits independently of other risk factors
- avoiding or limiting alcohol intake
- eating more vegetables, fruits and whole grains while minimising intake of red 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, such as breast and ovarian cancer
- completing the immunisation schedule for hepatitis B and HPV
- participating in cancer screening.

Further Information

- Our Mob and Cancer: Ways to help protect against cancer – Living a healthy lifestyle www.ourmobandcancer.gov.au/ways-to-help-protect-against-cancer/living-a-healthy-lifestyle
- For MBS item 715 Aboriginal and Torres Strait Islander health assessment templates, see RACGP's (2023) Resources to support health checks for Aboriginal and Torres Strait Islander people www.racgp.org.au/the-racgp/faculties/aboriginal-and-torres-strait-islander-health/guides/resources/2019-mbs-item-715-health-check-templates

1.2.2 Smoking

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

While the proportion of Aboriginal and Torres Strait Islander adults who smoke tobacco daily has declined from 48% in 2002 to 41% in 2018–19, it remains a leading risk factor for many types of cancer (AIHW & NIAA 2023f).

The rate of use of e-cigarettes (vaping) is increasing. First Nations people who had tried vaping were more likely to be male, younger (under 45 years of age) and living in urban and regional areas.

The use of e-cigarettes is rising across Australia, particularly amongst the youth. A study from 2017 found around 22% of First Nations secondary school students aged 12–17 years have tried vaping (DoHAC 2023).

Effective strategies to help people quit smoking include:

- structured interventions from health professionals
- referral to Quitline (13 78 48) for ongoing support. Aboriginal and Torres Strait Islander counsellors are available on request
- individual or group counselling programs, such as those offered by Quit: www.quit.org.au/
- nicotine replacement therapy and other pharmacological agents.

Further Information

- Find out more about the national Tackling Indigenous Smoking program, including information about vaping (e-cigarettes) and resources to support activities to quit smoking www.health.gov.au/our-work/tackling-indigenous-smoking
- Vaping and e-cigarette laws – What we are doing to reduce vaping rates and protect young people from the harms of vaping www.health.gov.au/topics/smoking-vaping-and-tobacco/about-vaping#what-were-doing
- National Tobacco Strategy 2023–2030 www.health.gov.au/resources/publications/national-tobacco-strategy-2023-2030

1.2.3 Immunisation

Some potentially preventable or screen-detectable cancers are more common among Aboriginal and Torres Strait Islander people than non-Indigenous Australians, including cancers associated with chronic infections such as hepatitis B and HPV (AIHW & NIAA 2023a; NCCI 2022; Lockwood et al. 2024).

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. 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 (DoHAC 2022a).

For immunisation to have the greatest benefit, a large proportion of the community must be fully immunised (DoHAC 2022b). Mainstream health services should work with local ACCHS to design and implement culturally appropriate strategies to increase awareness, facilitate access and encourage participation in relevant immunisation programs by Aboriginal and Torres Strait Islander people.

1.2.4 Individual assessment

For health professionals working within the primary healthcare sector, the MBS item 715 health assessment for Aboriginal and Torres Strait Islander people provides an ideal opportunity to assess cancer risk.

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

Understanding a patient's personal cancer risk level enables health professionals to recommend the most appropriate evidence-based prevention and early detection strategies. All patients should have their individual cancer risk assessed. This will usually occur in primary care in the first instance.

Cancer risk assessment should be repeated when major risk factors change (for example, when new family cancer history is identified). Sensitivity is required when discussing family cancer history (see Genetic counselling and testing, section 1.2.5).

For patients with an increased risk of developing cancer based on their family history, consider referral to a:

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

Further information

- Access Cancer Australia's online cancer risk assessment tools www.canceraustralia.gov.au/impacted-cancer/check-your-cancer-risk-online
    - Check your cancer risk tool. A 5-minute tool to assess how everyday lifestyle choices can affect cancer risk
    - Investigating symptoms of lung cancer – Interactive diagnostic tool
- Peter MacCallum Cancer Centre, iPrevent validated breast cancer risk assessment and risk management decision support tool www.petermac.org/iprevent

1.2.5 Genetic counselling and testing

Aboriginal and Torres Strait Islander people are less likely to participate in genetic counselling and testing than non-Indigenous Australians (Luke et al. 2022).

Culturally safe practice involves sensitivity when discussing family history and genetic testing, being aware that:

- it may be distressing for the patient to discuss members of the family who are part of the Stolen Generation, who are missing, or who are unknown
- it is important to recognise that the Aboriginal and Torres Strait Islander concept of family may include people who are not genetically related
- discussions of familial cancer may require a discussion of Men's Business and Women's Business in the same conversation, which may be uncomfortable for the patient
- the patient may be asked to refer to people who have died ('Sorry Business'), which may be uncomfortable for the patient
- the patient may be asked to either seek information about other people's cancer in the family or to consider passing information on to family members about the outcome of testing. These conversations away from the clinic may involve cultural taboos about cancer, Sorry Business and speaking about both Men's Business and Women's Business
- the types of questions asked may cause tension relating to research exposure and so may require more information about why the questions are necessary
- many Aboriginal and Torres Strait Islander peoples do not like to talk about cancer as it is perceived (for some) that where you talk about illness it manifests it further; that is, where you don't voice it, it will go away.

Aboriginal and Torres Strait Islander Health Workers and Health Practitioners can support access to genetic counselling and testing (Luke et al. 2022). It is important that an Aboriginal and Torres Strait Islander person being advised to undertake genetic testing or counselling is made aware as to how these might benefit their treatment and care pathway.

Further information

- Refer to Our Mob and Cancer website for consumer information about genes and cancer www.ourmobandcancer.gov.au/cancer-in-our-mob/why-did-i-get-cancer/genes-and-cancer
- The Indigenous Genomics Health Literacy Project (IG-HeLP), by QIMR Berghofer Medical Research Institute, developed health literacy resources, Your Blood, Your Story, Let's have a yarn about DNA, genes and genetic health www.qimrberghofer.edu.au/our-research/aboriginal-torres-strait-islander-health/ig-help/
- Information about referral for cancer genetics services – General practitioner referral guidelines for cancer genetics assessment: 1147-General practitioner referral guidelines for cancer genetics assessment | eviQ.

Implementation support checklist – Prevention and early detection

Do you or does your service:

- have a protocol/guidance for how to discuss cancer risk and family history in a culturally appropriate way?
- promote and assist Aboriginal and Torres Strait Islander people to access immunisations?
- routinely use the Medicare health assessment for Aboriginal and Torres Strait Islander people and incorporate strategies to reduce risk of cancer?
- work with local ACCHS and/or other Aboriginal and Torres Strait Islander health and community groups to promote awareness of cancer risk and encourage early help seeking?

(Cancer Australia 2020)

1.3 Screening

Increasing access to, and participation in, preventive healthcare and cancer screening is a priority for improving Aboriginal and Torres Strait Islander people's cancer-related outcomes (Cancer Australia 2023).

All primary healthcare professionals have a responsibility to encourage Aboriginal and Torres Strait Islander people to participate in screening programs appropriate to the individual's age and risk.

Aboriginal and Torres Strait Islander people have lower participation in screening programs than non-Indigenous Australians, with access to culturally competent health services, discrimination, distrust of Western medicine and distrust of screening tests being identified as barriers (AIHW & NIAA 2023c).

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

- encouraging health professionals to discuss screening and immunisation, including through MBS item 715 health assessments for Aboriginal and Torres Strait Islander people, and regular primary healthcare checks
- developing partnerships between screening programs and primary healthcare services, including ACCHS (Butler et al. 2022a)
- respecting cervical and breast cancer screening as Women's Business (Jaenke et al. 2021 Whop et al. 2022; Butler et al. 2022a), including option for self-collection for cervical cancer screening (Dutton et al. 2020; Whop et al. 2022)
- co-designed, innovative approaches to screening (Menzies 2020)
- having dedicated personnel and systems to facilitate recall and reminder processes
- quality improvement initiatives to improve access to, and 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 cancer care, particularly in regional or remote areas with smaller populations. Concerns may be addressed by:

- establishing relationships of trust with patients as a foundation
- reassuring people that health professionals abide by a privacy code of conduct
- providing options outside of the community setting
- promoting self-screening options (see Appendix A: Case study examples).

Mainstream health services should work with local ACCHS and others to design and implement culturally appropriate strategies to increase awareness, facilitate access and encourage participation in population-based cancer screening by Aboriginal and Torres Strait Islander people.

Further information

- Refer to the Australian Government webpage on the upcoming national lung cancer screening program www.health.gov.au/our-work/national-lung-cancer-screening-program https://www.health.gov.au/our-work/nlcsp
- Refer to the Australian Government webpage on cancer screening programs www.cancerscreening.gov.au/
- Contact your local Primary Health Network or Aboriginal and Torres Strait Islander Community-Controlled Health Service to find out about local opportunities to facilitate screening for cancer (note: bowel cancer screening and breast cancer screening are not delivered through Primary Health Networks) www.health.gov.au/our-work/phn/your-local-PHN

- For resources about bowel cancer screening for Aboriginal and Torres Strait Islander people www.cancer.org.au/bowelscreening/first-nations-communities
- For resources about breast cancer screening for Aboriginal and Torres Strait Islander women www.healthinfonet.ecu.edu.au/key_resources/resources/29362/?title=BreastScreen+Australia+campaign+for+Aboriginal+and+Torres+Strait+Islander+people&content_id=29362_1
- Refer to Cancer Australia’s consumer information resources:
    - Our Mob and Cancer website has a page dedicated to screening www.ourmobandcancer.gov.au/ways-to-help-protect-against-cancer/Screening-for-cancer
    - Checking for cancer – what to expect, explains what to expect while getting checked www.cancer.org.au/cancercareguides/for-aboriginal-and-torres-strait-islanders

1.4 Early detection

Timely diagnosis is vital for improving cancer survival rates/lowering mortality rates in the Aboriginal and Torres Strait Islander population.

In addition to lower screening rates, key factors that affect early detection in Aboriginal and Torres Strait Islander people include:

- limited knowledge about cancer, its symptoms and survivability
- patient beliefs, concerns or fears
- limited access to health services and cancer services in remote and regional areas (AIHW & NIAA 2023b)
- comorbidities masking cancer symptoms (Dasgupta et al. 2022).

Strategies for overcoming factors that affect prevention, screening and early detection of cancer in Aboriginal and Torres Strait Islander people are addressed in section 1.2, Risk reduction.

Further information

- For further information about Aboriginal Community Controlled Health Services refer to the National Aboriginal Community Controlled Health Organisation for contact details www.naccho.org.au/naccho-members/

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 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 that can mask cancer symptoms
- have multiple risk factors; for example, obesity, smoking a family history of cancer (see Risk factors, section 1.1)
- be of a younger age at presentation with breast or bowel cancer, compared to non-Indigenous Australians (Lew et al. 2022; Christie et al. 2023b)
- present with a later stage of disease.

The following factors may affect the presentation and investigative pathway, including whether the person maintains contact with health services:

- reluctance to discuss Men’s and Women’s Business in the presence of a member of the opposite gender (see section Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer: further considerations and Men’s and Women’s Business)
- feeling culturally unsafe in mainstream health services
- facing financial, transport or other barriers to accessing health services
- having family and community responsibilities
- experiencing feelings of discomfort or shame from heightened attention, sharing personal information, previous experiences or perceptions about cancer or mainstream medical 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 psychosocial, and cultural background
- relevant family history and all images
- diagnostic reports (old and new).

Working with the patient to establish their preferences, the referring clinician should:

- provide culturally appropriate and accessible information about steps involved in the investigation of cancer symptoms. This should also be shared with family supports and carers as appropriate
- connect the patient to an Aboriginal and Torres Strait Islander Health Worker or Health Practitioner, translator, and/or other support persons to facilitate attendance and communication at appointments
- provide information and referral to supportive care services (see Principle 4: Supportive care).

It is imperative for health services to ensure the patient's contact details are up to date at each visit to enable active follow-up. Timely follow-up regarding the status of the referral is essential.

Further information

- Cancer Australia consumer resources to support Aboriginal and Torres Strait Islander people with cancer include:
    - Cancer – what to expect. Information for Aboriginal and Torres Strait Islander people who have cancer www.cancer.org.au/assets/pdf/cancer-what-to-expect
    - Our Mob and Cancer website includes a webpage: Tests for cancer www.ourmobandcancer.gov.au/finding-out-you-have-cancer/tests-for-cancer
- Supportive care information is found at Principle 4: Supportive care. This includes:
    - Integrated Team Care program www.health.gov.au/our-work/integrated-team-care-program
    - Patient Assisted Travel Schemes www.healthdirect.gov.au/travelling-to-your-healthcare-appointment#resources

2.3 Optimal timeframes for investigations and referrals

Timeframes for completing investigations and referral to a specialist should be informed by evidence-based guidelines (where they exist), while recognising that shorter timelines for appropriate consultations and treatment can reduce a patient's distress.

Telehealth can be used to facilitate timely discussion and involvement of family members and carers in decision making within the optimal care timelines.

Health services should designate a staff member responsible for following up referrals and to stay connected with the patient to maintain engagement along the cancer pathway within optimal timeframes. The supportive and liaison role of the person's general practitioner, primary health care team, including ACCHS, coordinators and Aboriginal and Torres Strait Islander Health Workers or Health Practitioners in this process is critical (refer to Principle 5: Care coordination).

2.4 Support and communication

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.

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 and carers, at each step of the cancer care pathway.

It is important that Aboriginal and Torres Strait Islander communities and people with cancer, their carers and families are aware of the support services available and whom to contact in emergencies.

2.4.1 Supportive care

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, Hospital Liaison Officer or social and emotional wellbeing workforce.

The SCNAT-IP is useful for determining which support services are required by Aboriginal and Torres Strait Islander people (Garvey et al. 2015; Thewes et al. 2016). Assessment should be repeated throughout the cancer pathway, with referrals made as required.

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 groups and services in the local area may also help patients to make informed decisions about their support needs.

Specific needs that may arise at this step include:

- treatment for physical symptoms
- help with the emotional distress of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems, stress and adjustment difficulties, including referral to social and emotional wellbeing services and mental health services, and support groups
- 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.

For further information and links to resources, refer to Principle 4: Supportive care.

2.4.2 Communication with the patient, family and carer

For information about communicating with patients, families and carers, refer to the section Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer: further considerations: Cross-cultural communication section.

Further information

- Resources to support Aboriginal and Torres Strait Islander people with cancer include:
    - Our Mob and Cancer website, with information on cancer including cancer types, prevention, diagnosis, treatment, living with cancer, finding support and clinical trials www.ourmobandcancer.gov.au/
    - Checking for Cancer – what to expect. Information for Aboriginal and Torres Strait Islander people who have cancer www.cancer.org.au/assets/pdf/checking-for-cancer-what-to-expect-aboriginal-and-torres-strait-islander

Implementation support checklist – Presentation, initial investigations and referral

Do you or does your service:

- understand and have strategies to address potential barriers to early presentation of cancer symptoms in Aboriginal and Torres Strait Islander people?
- provide culturally appropriate information about steps involved in the investigation of cancer symptoms?
- facilitate access for Aboriginal and Torres Strait Islander people to appropriate support to help with accessing and attending specialist appointments?
- implement strategies to facilitate timely follow-up on the status of tests or referrals for investigation of cancer symptoms in Aboriginal and Torres Strait Islander people?

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer and for planning subsequent treatment. The guiding principle is to have close and sustained interactions between appropriate multidisciplinary team members who are responsible for determining the treatment plan, in collaboration with the patient, their families and carers, and taking into account 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 (See Principle 5: Care coordination).

3.1 Diagnostic workup

A range of diagnostic tests, assessments and investigations should be completed at this stage of the pathway. The exact recommended diagnostic workup depends on the type of cancer involved but may include physical examinations, blood and imaging tests, and biopsies.

Some procedures may require the patient to travel to receive care at a specialised centre, which could be arranged through the Patient Assistance Travel Scheme and supported by an Aboriginal and Torres Strait Islander Health Worker or Aboriginal Hospital Liaison Officer (refer to Principle 4: Supportive care).

All patients should be assessed for medical comorbidities during the diagnostic workup. These should be assessed and/or addressed in treatment planning alongside the individual's cancer care (Dasgupta et al. 2022).

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

3.1.1 Timeframe for completing the diagnostic workup

Timeframes should be informed by evidence-based guidelines and cancer-specific optimal care pathways, 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 relies on pathology following surgery because this provides the most accurate information; however, preliminary clinical staging may also be performed using laboratory and imaging tests undertaken during the diagnostic and treatment planning phase.

There should also be institutional guidelines for all aspects of staging, grading and/or risk stratification when reporting new diagnoses to cancer registries.

Details of cancer staging are outlined in each cancer-specific optimal care pathway.

Further Information

- Visit Cancer Institute of NSW's website for information about understanding the stages of cancer www.cancer.nsw.gov.au/about-cancer/cancer-basics/stages-of-cancer
- Refer to cancer-specific optimal care pathways at www.canceraustralia.gov.au/optimal-cancer-care-pathways

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 team member to the patient
- nominate a team member to coordinate patient care and identify this team member 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, including ACCHS.

3.3.2 Responsibilities of individual team members

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

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

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

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

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

3.3.3 Members of the multidisciplinary team

A multidisciplinary team is a team of doctors, nurses and other allied health professionals with expertise in the relevant cancer types. Multidisciplinary care is considered best practice in the treatment planning and care for patients with cancer. Multidisciplinary care involves all relevant health professionals discussing options and making joint decisions about treatment and supportive care to develop a personalised treatment plan, taking into account the personal preferences of the patient. A team approach to cancer care can reduce patient mortality and improve their quality of life (Cancer Australia 2024c).

For Aboriginal and Torres Strait Islander patients, it is essential that the multidisciplinary team includes a person experienced in providing culturally appropriate care to this population. This will preferably be an Aboriginal and/or Torres Strait Islander Health Worker or Health Practitioner, Aboriginal Hospital Liaison Officer, or Aboriginal and Torres Strait Islander staff member. Aboriginal and Torres Strait Islander patients should be given the choice of their involvement in the discussion. Studies consistently identify the value of Aboriginal and Torres Strait Islander staff being present and playing an active role at all steps of the cancer care pathway (Cramb et al. 2023; Green et al. 2021; Chynoweth et al. 2020; Sanjida et al. 2022; Ristevski et al. 2022; Olver et al. 2022; Anderson et al. 2021; Butler et al. 2023; De Witt et al. 2018; Hla et al. 2020; Christie et al. 2023a).

Where possible, the team should invite the patient's preferred general practitioner or primary care provider, including from ACCHS, used by the patient to attend or contribute information to multidisciplinary team meetings.

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

Also refer to Principle 3: Multidisciplinary care.

3.3.4 The optimal timing for multidisciplinary team planning

All patients with a newly diagnosed cancer should be discussed by the multidisciplinary team. The level of discussion may vary depending on both clinical and psychosocial factors.

Good preparation of materials and information in advance of multidisciplinary team meetings is essential. Results of all relevant tests, imaging and assessment of comorbidities should be available for discussion. The care coordinator or treating clinician should also present information about the patient's concerns, preferences and social circumstances at the meeting (Cancer Australia 2024b).

Details regarding optimal timing for multidisciplinary team planning are outlined in each cancer-specific optimal care pathway.

Further information

- Best practice in multidisciplinary care www.canceraustralia.gov.au/clinical-best-practice/multidisciplinary-care
- Cancer-specific optimal care pathways www.canceraustralia.gov.au/optimal-cancer-care-pathways
- Cancer Australia information resources regarding treatment for patients, their families and carers:
- Our Mob and Cancer website has a page dedicated to multidisciplinary team care www.ourmobandcancer.gov.au/treating-cancer/which-health-professionals-will-you-see/multidisciplinary-team

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.

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.

For further information and resource links, refer to Principle 7: Research and clinical trials.

Further information

- Information about research and clinical trials for Aboriginal and Torres Strait Islander patients, their families and carers www.ourmobandcancer.gov.au/treating-cancer/research-and-clinical-trials/research-and-clinical-trials-for-our-mob
- For the report of the Aboriginal and Torres Strait Islander People with Cancer – Clinical Trial Access Initiative (2022) www.menzies.edu.au/icms_docs/332413_Aboriginal_and_Torres_Strait_Islander_People_with_Cancer_Clinical_Trial_Access_Initiative_Consultancy_Report_for_ReViTALISE_Project_July2022.pdf

3.5 Support and communication

3.5.1 Supportive care

A comprehensive supportive care assessment should be undertaken and documented at the time of diagnosis. This assessment should align to each of the principles of care previously described within this document, to help support prospective treatment planning. See section on validated screening tools in Principle 4: Supportive care.

A number of specific needs may arise for the patient at this time:

- assistance for dealing with psychological and emotional distress while adjusting to the diagnosis, including support for families or carers who are distressed by the patient's cancer diagnosis
- discrimination uncertainty may make the Aboriginal and Torres Strait Islander patient less inclined to seek regular medical care
- support for discussion of Men's and Women's Business, e.g. fertility preservation in treatment planning
- management of physical symptoms such as pain and fatigue (Australian Adult Cancer Pain Management Guideline Working Party 2019)
- specific spiritual needs that may benefit from the involvement of pastoral/spiritual care
- financial and employment issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members).

Refer to Principle 4: Supportive care, 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 supports and carer(s)

Refer to the key points outlined in the section Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer: further considerations: Cross-cultural communication to support this step.

It is important to 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.

The following information should be effectively conveyed to the patient, their family and carers to support informed decision making:

- individualised tumour-specific information (supported by culturally appropriate resources as available)
- the recommended timeframe for diagnosis and treatment
- information about supportive care and care coordination
- information on the benefits of multidisciplinary care, including that the patient's health and supportive needs information will be available to the team for discussion at multidisciplinary team meetings.

The lead clinician should:

- establish if the patient has a regular or preferred general practitioner
- provide the patient with contact details of a key contact person within the treating team and/or the care coordinator
- offer advice on how to access information and support from websites, community and national cancer services and support groups for both patients and carers
- 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, where the patient agrees, the services of a medically trained interpreter and/or an Aboriginal and/or Torres Strait Islander Hospital Liaison Officer or Health Worker should be engaged before proceeding.

Further information

- For guidance on delivering diagnostic information to Aboriginal and Torres Strait Islander patients, their family and carers in a culturally safe way, see Cancer Australia resources www.canceraustralia.gov.au/key-initiatives/aboriginal-and-torres-strait-islander-people/culturally-safe-communication-skills/delivering-diagnosis

3.5.3 Communication and coordination with the general practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the person’s primary care provider regarding the treatment plan and recommendations from the multidisciplinary team
- invite the primary care provider to participate in multidisciplinary team meetings (consider using video or teleconferencing)
- notify the primary care provider, Aboriginal and/or Torres Strait Islander Health Worker or Hospital Liaison Officer and family/carer if the person is not able to 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.

Refer to Principle 5: Care coordination.

Implementation support checklist – Diagnosis, staging and treatment planning

Do you or does your service:

- understand and respond to cultural factors that may influence decision making by Aboriginal and Torres Strait Islander people?
- offer the option for patients to see a health professional of the same gender as the patient?
- routinely identify Aboriginal and Torres Strait Islander patients during multidisciplinary treatment planning meetings?
- have expertise in culturally appropriate care on the multidisciplinary team?
- use culturally appropriate care coordination to support timely diagnostic workup appropriate to the cancer type?
- invite the patient's preferred primary care provider to attend or contribute information to the multidisciplinary team meeting? (may be via video or teleconference)
- consider suitable clinical trials and provide culturally appropriate information about clinical trials?
- collect and use patient-reported outcome and experience measures relevant to Aboriginal and Torres Strait Islander people with cancer?

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
- anticancer 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 treatment intent should be established within the initial multidisciplinary team meeting, documented in the patient's medical record, and then conveyed appropriately to the patient, their family and carers as appropriate.

If not occurring already, discussion regarding advance care planning should be initiated with patients and their carers at this stage. Advance care planning should be encouraged at all stages of the care continuum of a life-threatening illness, with Aboriginal and Torres Strait Islander patients empowered to make informed choices. This might include involving carers, family and community members in decision making. A patient can change their plan at any stage. Refer to Advance care planning, section 6.5.

4.2 Treatment options

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

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

- the timing and duration of treatment
- travel and accommodation needs
- possible work, caring or education commitments
- cost
- cultural obligations, including family and community.

At this step, the following should occur to support communication and care coordination as required:

- engagement with Aboriginal and Torres Strait Islander Health Workers and Health Practitioners or Aboriginal Hospital Liaison Officer
- engagement with interpreter services
- providing culturally appropriate resources to support decision making
- the involvement of spiritual advisors, traditional healers and traditional medicine (see Traditional Healing, section 4.8).

Referral to specialised centres and/or the use of tele-oncology may be considered to facilitate access to the recommended treatment options outlined in the cancer-specific optimal care pathways.

Further information

- Cancer Australia resources include:
  - Optimal care pathways for each cancer www.canceraustralia.gov.au/optimal-cancer-care-pathways
  - Our Mob and Cancer website includes a webpage: Treating cancer in our mob www.ourmobandcancer.gov.au/treating-cancer/How-is-cancer-treated
- View Cancer Council's Making decisions about treatment resource for Aboriginal and Torres Strait Islander people www.cancercouncil.com.au/wp-content/uploads/2023/02/Making-decisions-about-treatment-Aboriginal-2022.pdf
- See Clinical Oncology Society of Australia's Clinical practice guidelines for tele-oncology: www.cancer.org.au/clinical-guidelines/teleoncology

4.3 Optimal timeframes for treatment

Timeframes should be informed by evidence-based guidelines and cancer-specific optimal care pathways (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 Pain management

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

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

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

- being proactive about offering patients pain relief
- offering the option for patients to discuss their pain and pain management with a health professional of the same gender, wherever possible
- using oral pain relief options if preferred by the patient, where appropriate
- developing and/or using a pain tool that is culturally appropriate for the local community
- fully explaining the options, usage and side effects of pain relief
- providing information about services that can assist with pain management or further questions, particularly when pain management is happening outside of the hospital environment
- health professionals also need to consider the effects of intergenerational trauma and the psychosocial aspects of pain that often exacerbate perceived pain; management of same may include ‘connecting to Country’ and traditional beliefs before traditional medical interventions.

Further guidance regarding pain management is provided in detail in Pain management, section 7.1.2.

4.5 Palliative care

Patients should receive timely and appropriate referral to palliative care services, including for pain management (see Pain management, section 7.1.2). 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.

Further guidance and resources on palliative care is provided in Step 7 of the pathway.

4.6 Research and clinical trials

All patients should be offered the opportunity to participate in a clinical trial or clinical research, if appropriate, as a part of their treatment. Refer to Research and clinical trials, section 3.4 for further information.

4.7 Place of care

For Aboriginal and Torres Strait Islander people living in regional and remote areas, the prospect of travelling to major cities for treatment can influence decision making regarding treatment. Place of care is particularly important in this context and can include:

- home visits
- outreach services and/or mobile clinics, including those based in ACCHS
- telehealth and tele-oncology services

Telehealth can be used to facilitate timely discussion and involvement of family members and carers in decision making within the optimal care timeline.

Further information

- Cancer Australia's Our Mob and Cancer resources – Leaving mob for treatment www.ourmobandcancer.gov.au/treating-cancer/leaving-mob-for-treatment

4.8 Traditional healing

Many Aboriginal and Torres Strait Islander traditional medicine and healing practices (also referred to as 'bush medicine') are currently used throughout Australia. Aboriginal and Torres Strait Islander people may use traditional medicines and healing practices, not only as a means for cancer treatment or symptom relief (such as for symptom relief from chemotherapy or stress by people with cancer), but also to maintain a connection with their culture, ancestors and spirituality (Gall et al. 2018; Gall et al. 2019).

It should be noted that Australia currently lacks policies regarding the use of Aboriginal medicine; therefore, there are no established accreditation, qualification or registration processes for traditional healers. Many alternative therapies and some traditional and complementary therapies have not been assessed for efficacy or safety.

The lead clinician should discuss and document in the medical records the patient's use (or intended use) of traditional or complementary or alternative medicine (CAM) therapies not prescribed by the multidisciplinary team in order to identify any potential toxicity or drug interactions, particularly when plant-based therapies are involved.

Supporting discussion and decision making may include:

- 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)
- inclusion of Aboriginal and Torres Strait Islander Health Workers, Health Practitioners or Aboriginal Hospital Liaison Officers and other support persons, as per patient preference.

It is an advantage to all concerned to have patients openly discuss traditional medicine and CAM therapies, secure in the knowledge that they will continue to receive support and understanding from their treatment team (Cancer Australia 2010). An Aboriginal and Torres Strait Islander patient may not be forthcoming about their use, or intended use, of traditional medicine and/or CAM therapies if they perceive health practitioners to be sceptical or opposed. This carries its own risk if the practice is not accounted for in treatment planning (De Witt et al. 2022).

Further information

- See the Cancer Australia webpage on Complementary therapies www.canceraustralia.gov.au/impacted-cancer/treatment/complementary-therapies
- See Clinical Oncology Society of Australia's position statement on the use of complementary and alternative medicine by cancer patients Microsoft Word - COSA_ CAM Position Statement_FINAL
- For systematic reviews into the use of cultural medicine and healing practices refer to:
  - The role of traditional medicine practice in primary health care within Aboriginal Australia: a review of the literature www.link.springer.com/article/10.1186/1746-4269-9-46
  - Traditional and complementary medicine use among Indigenous cancer patients in Australia, Canada, New Zealand, and the United States: A systematic review www.journals.sagepub.com/doi/10.1177/1534735418775821

4.9 Support and communication

4.9.1 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 (see validated screening tools in Principle 4: Supportive care).

The supportive care requirements for cancer patients vary significantly between tumour types, stage of disease and different populations. As such, providers need to be responsive and reassess individual patients' needs at each step of the cancer pathway.

Refer to Principle 4 for detailed information about providing supportive care to Aboriginal and Torres Strait Islander people affected by cancer.

4.9.2 Communication with patient, family supports and carer(s)

In addition to the key points outlined in the section Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer: further considerations: Cross-cultural communication section, the lead clinician should:

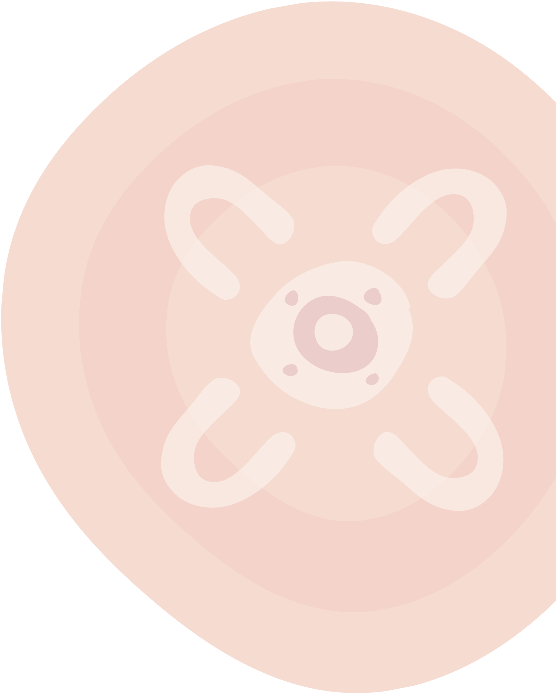
- discuss the treatment plan with the patient and carer, including the intent of treatment and expected outcomes, including discussion of prognosis
- provide a written copy or other accessible form of the treatment plan
- provide information about potential side effects of treatment and what can be done about them, including self-management strategies and emergency contacts.

4.9.3 Communication with the general practitioner

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

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

Refer to Principle 5: Care coordination for further information.



Step 5: Care after initial treatment and recovery

This step relates to the transition from active treatment to post-treatment care. During this phase, patients are provided with a treatment summary and follow-up care plan.

While terms such as ‘cancer survivor’ and ‘survivorship care’ may commonly be used during this phase, it’s important to consider that the term ‘survivor’ may have negative connotations for Aboriginal and Torres Strait Islander people for historical reasons.

5.1 Transitioning from active treatment

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 and in other cases a shared follow-up care arrangement with their general practitioner may be appropriate.

During this phase, people affected by cancer often face issues that are different from those experienced during active treatment for cancer. During cancer treatment, it is important to start discussions and plan for life after treatment.

Many people with cancer experience persisting side effects at the end of treatment. Late effects may occur months or years later and are dependent on the type of cancer treatment. Emotional and psychological issues include:

- distress
- anxiety and fear of cancer recurrence (Butler et al. 2023)
- depression
- cognitive changes
- altered relationships
- difficulties with returning to work or study, and financial hardship.

For Aboriginal and Torres Strait Islander people, healing and culture are inextricably linked. The pathway to healing is through cultural activity. Cultural identity and practices, being on Country, connection to Country, and involvement in family and community are critical elements in cultural healing programs (Meiklejohn et al. 2018; Meiklejohn et al. 2019; Ristevski et al. 2020).

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

People affected by cancer need to see a specialist for regular follow-up, often for five or more years after their cancer treatment finishes, to enable:

- surveillance and prevention of recurrent, secondary and/or new cancers
- screening and assessment for medical and psychosocial side effects
- interventions to deal with other consequences of cancer and cancer treatments
- coordination of care between all providers to ensure the patient's needs are met (Cancer Australia 2024b).

There are challenges for remote patients in accessing specialists for follow-up after cancer treatment finishes. At rural and remote health clinics, unscheduled reviews may involve multiple steps to organise and can be influenced by outreach assessment and appointment wait times. It's important to acknowledge that cultural obligations may affect when a patient can attend a specialist appointment, which may delay timely investigations and any subsequent treatment.

Tele-oncology and telehealth appointments and/or mobile clinics, including those supported by local ACCHS, should be used where possible.

Strategies to assist Aboriginal and Torres Strait Islander people with cancer in the transition to survivorship include:

- engaging Aboriginal and Torres Strait Islander Health Workers and Health Practitioners, primary healthcare coordinators, and/or Aboriginal Hospital Liaison Officers to continue to support transition, including navigation and care coordination, after treatment ends
- providing culturally appropriate resources about healthy lifestyle, such as smoking cessation
- patient, family and carer education and resources about managing health needs
- information about relevant available services, including support groups, 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 Clinical Oncology Society of Australia's Model of Survivorship Care www.cosa.org.au/media/332340/cosa-model-of-survivorship-care-full-version-final-20161107.pdf
- Access Cancer Australia's Principles of Cancer Survivorship www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/principles-cancer-survivorship
- Access the Aboriginal and Torres Strait Islander Healing portal www.healthinfonet.ecu.edu.au/related-issues/healing
- For information for patients, access Our Mob and Cancer – Life with and after cancer, including information on follow-up and healthy living after cancer www.ourmobandcancer.gov.au/life-with-and-after-cancer

5.2 Post-treatment care planning

5.2.1 Treatment summary

When the initial treatment is finished, the patient, their carers (as appropriate) and general practitioner or primary care provider, including ACCHS, should receive a treatment summary outlining:

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

5.2.2 Follow-up care

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

It is important that post-treatment care is evidence-based and consistent with guidelines.

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

Responsibility for follow-up care should be agreed between the lead clinician, the person's general or primary practitioner, relevant members of the multidisciplinary team (including any relevant care coordinator) and involve shared decision making with the patient, their family and carers.

The follow-up care plan outlines:

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

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

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

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

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

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

Refer to Advance care planning, section 6.5.

Refer to Multidisciplinary palliative care, section 7.1.

5.3 Research and clinical trials

All patients should be offered the opportunity to participate in a clinical trial or clinical research, if appropriate, as a part of their post-treatment care.

Refer to Research and clinical trials, section 3.4, for further information. In addition to providing information about a trial and how a patient might participate, the potential advantages and risks must be communicated to, and understood by, the patient and their family and carers as required.

5.4 Support and communication

5.4.1 Supportive care

An individualised clinical assessment is required to assess and meet the needs of Aboriginal and Torres Strait Islander people with cancer, their families and carers; referral should be as required. Refer to Principle 4: Supportive care.

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
  - support adopting healthy lifestyle behaviours that can reduce cancer risk, such as quitting smoking, reducing alcohol consumption, consuming a healthy diet, being physically active and being sun smart may be required.
- Psychological needs
  - emotional distress arising from fear of disease recurrence (Butler et al. 2023), changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns
  - anxiety/depression, interpersonal problems, stress, and adjustment difficulties may require referral to a counsellor or mental health professional.
- Social/practical needs
  - difficulties with returning to work or study may require extra support
  - increased community support may be required as the patient recovers from treatment.

Also consider carers' support needs in the post-treatment context. Refer to discussion on validated screening tools in Principle 4: Supportive care.

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.

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.

When supporting a patient to plan rehabilitation, health practitioners should:

- provide information and provide options to support informed decision making
- ensure patient cultural safety
- ensure privacy concerns are addressed
- involve family and carers at the patients request
- involve Aboriginal and Torres Strait Islander Health Workers and Practitioners
- engage translators as required.

Rehabilitation plans should be shared with care coordinators and primary health care providers, including ACCHS, that the patient uses to help support adherence.

5.4.3 Communication with the patient, carer(s) and family and supports

In addition to the key points outlined in the Supporting the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer: further considerations: Cross-cultural communication section, the general or primary practitioner should:

- consider that the term 'survivor' may have negative connotations for Aboriginal and Torres Strait Islander people for historical reasons
- discuss the management of any of the issues identified in section 5.4.1 (Supportive care)
- 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.

Refer to Principle 5: Care coordination.

Implementation support checklist – Care after initial treatment and recovery

Do you or does your service:

- routinely engage input from an identified health professional or other health professional with expertise in culturally appropriate and responsive care to provide support for people after completion of active treatment for cancer?
- discuss patient beliefs and definition of living well to ensure health services are working towards the patient's ideal outcome?
- provide culturally appropriate information to help Aboriginal and Torres Strait Islander people understand plans for follow-up care and how to access support once initial treatment has been completed?

Step 6: Managing recurrent, residual or metastatic disease

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

Patients who present with recurrent or metastatic disease should be managed by a multidisciplinary team and offered timely referral to appropriate physical, practical and emotional support.

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 to a specialist centre for recurrent or metastatic disease, as appropriate. Where relevant, the multidisciplinary team should include a person experienced in providing culturally safe and responsive care. Refer to Members of the multidisciplinary team, 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 tele-oncology 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
- to provide symptom palliation.

To allow the patient to make informed decisions, health professionals need to ensure the patient and their carers receive culturally appropriate information on the stage of disease and the treatment options available. If not already actioned, discussion regarding advance care planning should be initiated (see Advance care planning, section 6.5).

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 Advance care planning, section 6.5, and Pain management, section 7.1.2.

6.5 Advance care planning

Advance care planning is important for all patients with a cancer diagnosis. Where appropriate, patients, their family or carer should be encouraged to think and talk about their healthcare values and preferences and consider developing an advance care directive to convey their preferences for future health care (DoHAC 2022c. These conversations should begin soon after the cancer diagnosis and can be revisited intermittently throughout the disease course. Importantly, advance care planning is a continuum rather than a single health event.

Further information

- Refer patients and carers to Advance Care Planning Australia or to the Advance Care Planning National Phone Advisory Service on 1300 208 582
    - Advance care planning for Aboriginal and Torres Strait Islander peoples – Information for individuals, carers and health providers on culturally sensitive care through advance care planning www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-for-aboriginal-and-torres-strait-islander-peoples

6.6 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 (NCCI 2024). Refer to Multidisciplinary palliative care, section 7.1.

6.7 Research and clinical trials

All patients should be offered the opportunity to participate in a clinical trial or clinical research if appropriate. Refer to Research and clinical trials, section 3.4.

6.8 Support and communication

6.8.1 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. Refer to Principle 4: Supportive care.

6.8.2 Rehabilitation

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

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. Refer to Rehabilitation and recovery, section 5.4.2.

6.8.3 Communication with the patient, carer(s) and family supports

The lead clinician should ensure there is adequate discussion with the patient and their family/carer about the diagnosis and recommended treatment, including the intent of treatment and possible outcomes, the likely adverse effects and the supportive care options available. Refer to Principle 6: Communication.

If not already actioned, initiate a discussion regarding advance care planning with the patient and their family/carer, if appropriate. Refer to Advance care planning, section 6.5.

Step 7: End-of-life care

Step 7 is concerned with maintaining the person's quality of life and meeting their health, supportive, cultural and spiritual care needs as they approach the end of life, as well as the needs of their family and carers.

Engagement with culturally appropriate palliative care services can improve the experiences of Aboriginal and Torres Strait Islander people affected by cancer, as well as those of their families and carers.

End-of-life care is appropriate when the person's symptoms are increasing and functional status is declining. The value of palliative care in improving symptom management and quality of life at this step should be emphasised to patients, their families and their carers.

7.1 Multidisciplinary palliative care

If not already organised, a referral to palliative care services should be considered at this stage, including shared decision making with patients, their families and carers about end-of-life care planning (including pain management) and transitioning planning.

The patient's general or primary care practitioner, including ACCHS, should be kept fully informed and involved in major developments in the patient's end-of-life journey.

The multidisciplinary palliative care team should include an expert in providing culturally safe and responsive care to Aboriginal and Torres Strait Islander people, such as an Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Hospital Liaison Officer.

An understanding of the principles of a palliative approach to care needs to be shared by the multidisciplinary team, the patient, their family and carers to empower them and support their informed decision making.

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.

If not already in place, the patient and carer should be encouraged to develop an advance care plan (refer to Advance care planning, section 6.5). 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 Return to Country, section 7.1.1)
- the appropriate person within the family who is to provide care and consent and to make funeral arrangements
- requirements for cultural ceremonies and practices, such as outdoor spaces.

If the patient is being cared for in a health service environment, policies regarding the number of visitors allowed at one time and/or visiting hours may need to be relaxed to accommodate extended family and kin groups wanting to pay their respects.

Wherever possible, and as 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. Also ensure culturally safe communication that respects Aboriginal and Torres Strait Islander sensitivities around discussion of death and dying. Refer to Principle 6: Communication.

Further information

- Our Mob and Cancer website with a page on Sorry Business www.ourmobandcancer.gov.au/sorry-business
- Palliative Care Australia resources: www.palliativecare.org.au including comprehensive Aboriginal and Torres Strait Islander-specific resources, including videos www.palliativecare.org.au/resource/aboriginal-and-torres-strait-islander-peoples-palliative-care-resources/
- Aboriginal and Torres Strait Islander Discussion Starter – Working Out What's Right For You www.palliativecare.org.au/campaign/aboriginal-torres-strait-islander-discussion-starter/
- Aboriginal and Torres Strait Islander Discussion Starter Cards www.palliativecare.org.au/product/aboriginal-and-torres-strait-islander-discussion-starter-cards

- Advance Care Planning Australia's advance care planning for Aboriginal and Torres Strait Islander peoples resources <www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-for-aboriginal-and-torres-strait-islander-peoples
- The Palliative Care Education and Training Collaboration www.pepaeducation.com provides:
    - education and training about the palliative approach to care for Cancer Support Workers and Aboriginal and Torres Strait Islander Health Workers and Health Practitioners in Aboriginal Community Controlled Services in its Indigenous Program of Experience in the Palliative Approach (IPEPA) IPEPA - PEPA
    - Cultural Considerations: Providing end-of-life care for Aboriginal and Torres Strait Islander peoples PEPA_CulturalConsiderationsFlipbook_Web.pdf

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 to them, their families and communities. It is essential that this be respected 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, including ACCHS, and arranging:

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

The palliative care planning should support the patient, their family and carers to identify cultural practices they want to include in the end-of-life process. A patient's choice around their cancer experience and around their quality of life in end-of-life palliative care, including a return to Country, may not be what their carers or family accept or are able to accommodate. They may not have time to put all supports in place, particularly in remote areas. Achieving a resolution in this context will require sensitivity and preferably the support of Aboriginal and Torres Strait Islander staff.

Wherever possible, led by Aboriginal and Torres Strait Islander staff, the multidisciplinary palliative care team should work with the patient, their family and carers to develop strategies to support these requests.

7.1.2 Pain management

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

Aboriginal and Torres Strait Islander people experiencing pain may not actively complain about it or communicate pain in ways recognised by non-Indigenous people. Aboriginal and Torres Strait Islander staff (including staff of a particular gender in relation to Men's and Women's Business) are well placed to understand the distinct ways Aboriginal and Torres Strait Islander patients might communicate pain, and otherwise have the trust of patients that better supports the communication of pain and pain relief needs.

A lack of complaint about pain or request for pain relief should not be interpreted as a lack of need. Aboriginal and Torres Strait Islander people may be quiet and reserved because they:

- have a cultural preference for bravery and not wanting to appear weak, particularly for people in leadership roles
- associate pain with shame and stigma due to the health issue it is associated with and lack of trust in non-Indigenous health professionals, or are otherwise challenged to assert their pain needs to this cohort
- are challenged to describe the pain and embarrassed at the potential of being misunderstood
- are challenged to understand clinical descriptions of possible side effects and have not had the medication and its side effects adequately explained to them
- fear asking for pain relief will associate them with negative stereotypes about Aboriginal and Torres Strait Islander people (Arthur et al. 2019)
- are embarrassed because the pain relates to body areas that are understood as Men's and Women's Business, and discussion requires involving people of another gender
- are already practising cultural forms of pain relief, including centering, which involves being still and entering a deep spiritual and psychological focus to shut the pain out.

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

- there are significant cultural practices regarding which family members (may include Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners) can assist with providing pain relief
- Aboriginal and Torres Strait Islander people (e.g. family, carers) may be hesitant to administer pain relief to other people
- 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)
- security concerns about the safe storage of medications in some family or community contexts.

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

- being proactive about offering patients pain relief
- offering the option for patients to discuss their pain and pain management with a health professional of the same gender, wherever possible
- using oral pain relief options if preferred by the patient, where appropriate
- developing and/or using a culturally appropriate pain tool
- fully explaining the options, usage and side effects of pain relief in plain language
- involving the patient's family and carers in discussions
- providing information about services that can assist with pain management, or answer questions to the patient, their families and carers 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 and supplemented with written copies. To support the patient and carers, provide access to necessary resources, such as medical supplies, instructional videos, step-by-step manuals and online support materials for home care. Refer to Principle 4: Supportive care.

7.1.3 Practices around death and dying

The practices observed around death and dying vary significantly between individuals and Aboriginal and Torres Strait Islander communities. Health services should discuss cultural preferences with patients, their families and carers, and are encouraged to use Aboriginal and Torres Strait Islander staff and ACCHS to better understand how to 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 several 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 Aboriginal and Torres Strait Islander staff and/or ACCHS 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 Aboriginal and Torres Strait Islander staff and/or ACCHS 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 acknowledge that some Aboriginal and Torres Strait Islander health professionals or other staff may have cultural obligations that will cause conflict with their professional role and may require leave for enacting cultural responsibilities following the death of a patient and/or family member.

7.1.4 Voluntary assisted dying

A person who is suffering in the late stages of advanced disease and who meets strict criteria can request access to voluntary assisted dying. It must be voluntary and initiated by the person themselves.

As voluntary assisted dying is legislated by state and territory governments, it is essential to know the law and rules around this choice in the state or territory where the patient lives (Cancer Council 2020). Contact your state's health department for the latest voluntary assisted dying information relevant to your state.

For further information about culturally competent communication that respects Aboriginal and Torres Strait Islander sensitivities around discussion of death and dying, refer to Principle 5: Care coordination.

Further information

- Contact your state's health department for the latest voluntary assisted dying information relevant to your state www.health.gov.au/about-us/contact-us/local-state-and-territory-health-departments

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 Research and clinical trials, section 3.4, for further information.

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. Supportive care needs should be re-assessed at this time with validated tools. Refer to discussion on validated screening tools in Principle 4: Supportive care.

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

- **Physical needs**
  - decline in mobility or functional status affecting the patient's discharge destination will need to be considered.
- **Cognitive dysfunction and personality and behavioural changes**
  - there may be behavioural changes or confusion/delirium, and specific management by a neuro-psychologist/psychiatrist is often required during this stage of disease progression.
- **Psychological needs**
  - patients, carers, families and other supports 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 assessment and supportive psychotherapy.

- **Social/practical needs**
  - support may be required for the practical, financial and emotional impacts on carers, Elders and family members resulting from the increased care needs of the patient
  - specific support should be provided for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs
  - potential isolation from normal support networks, particularly for rural and remote patients who have been staying away from home for treatment, may be an issue. Many Aboriginal and Torres Strait Islander people with cancer speak of being treated or feeling like an outcast in their community because of the stigma associated with cancer. Social isolation may require referral to counselling services.
- **Information needs**
  - communication about the death and dying process (using culturally appropriate terms) and what to expect is important
  - all members of the care team and the patient's ACCHS 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.

7.3.2 Communication with the patient, carer(s) and family supports

Communication around end-of-life care 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, family and carers with the contact details of a palliative care service, or initiate telehealth or a conference call with the local palliative care team while the patient is present (an introduction may facilitate discussions on, or referral to, palliative care)
- ensure the family and carers understand and have written or other accessible-format information about the supportive care and pain management plans, and provide a culturally safe and responsive opportunity to address any questions or concerns with providing care.

7.3.3 Communication with the general practitioner

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

Further information

- Palliative Care Australia question prompt cards developed for Aboriginal and Torres Strait Islander peoples can be found at www.palliativecare.org.au/product/aboriginal-and-torres-strait-islander-discussion-starter-cards/

Implementation support checklist – Managing recurrent, residual or metastatic disease and end-of-life care

Do you or does your service:

- have agreed strategies and information to help patients understand their situation at the point of recurrence or diagnosis of residual or metastatic disease?
- use culturally appropriate language and strategies to discuss death and dying with Aboriginal and Torres Strait Islander people?
- consider cultural beliefs and practices in the management of pain?
- have culturally appropriate strategies and pathways to identify and respond to the needs and preferences of Aboriginal and Torres Strait Islander patients at the end of life?
- support and facilitate provision of cultural practices for Aboriginal and Torres Strait Islander people, their families, carers and community at end of life?

Contributors and reviewers

For this Edition

Our thanks to all the Aboriginal and Torres Strait Islander people, healthcare professionals and organisations who contributed to the refresh and update of this optimal care pathway.

We particularly want to acknowledge Karabena Consulting Trust and Professor Jacinta Elston, Advisor, Aboriginal and Torres Strait Islander Cancer Control, who led the update, and the significant contribution of the following stakeholders:

Ms Casey Luttrell, Senior Project Officer, NACCHO

Ms Shannon Gleeson, Project Manager, Palliative Care, NACCHO

Mr Andrew Redfern, Associate Professor of Medical Oncology, Harry Perkins Institute of Medical Research and WA Health

Mr Frankie Clive, Executive Manager, Primary Health Care Apunipima Cape York Health Council

Ms Katherine Quartermaine, Consumer, Retired RN and community advocate

Mr Hilton Mtanda, Social and Emotional Wellbeing Manager, Derbarl Yerrigan

Ms Beth Manchester, Cancer Support Coordinator, Derbarl Yerrigan

Associate Professor Craig Underhill, Regional Oncology lead, Victorian Comprehensive Cancer Centre Alliance

Cancer Australia's Leadership Group on Aboriginal and Torres strait Islander Cancer Control (this edition)

Associate Professor Lisa Whop (Chair), Senior Research Fellow, National Centre for Epidemiology and Population Health, Australian National University College of Health and Medicine

Mr Karl Briscoe, CEO, National Association of Aboriginal and Torres Strait Islander Health Workers and Health Practitioners (NAATSIHWP)

Professor Tom Calma AO, National Coordinator, Tackling Indigenous Smoking

Dr Dawn Casey, Deputy CEO, National Aboriginal Community Controlled Health Organisation (NACCHO)

Ms Kristine Falzon, Executive Project Manager, Waminda South Coast Women's Health and Wellbeing Aboriginal Corporation

Professor Gail Garvey, Professor in Indigenous Health Research, Faculty of Medicine, University of Queensland

Ms Tanya McGregor, Director, Aboriginal Health Strategy, SA Department for Health and Ageing

Mr Rob McPhee , Chief Executive Officer, Danila Dilba Health Service

Mr Trevor Pearce, Consumer; Chief Executive Officer, Mullum Mullum Indigenous Gathering Place

Ms Leanne Pilkington , Senior Program Officer, South Metropolitan Health Service WA

Ms Kate Thomann , Assistant Secretary, First Nations Policy Branch, Social Policy Division, Department of the Prime Minister and Cabinet

Ms Kelly Trudgen, Nursing Director, Aboriginal & Torres Strait Islander Health Division, Queensland Health; Senior Health Workforce Advisor, Queensland Aboriginal and Islander Health Council

Expert Membership (previous edition)

We acknowledge the leadership of the Expert Working Group and Cancer Australia's Leadership Group on Aboriginal and Torres Strait Islander Cancer Control, who provided high-level expert advice and guidance throughout the development of this optimal care pathway.

Expert Working Group

Professor Jacinta Elston (Co-Chair), Pro Vice-Chancellor (Indigenous) and Yulendj Indigenous Engagement Unit, Monash University (Vic)

Associate Professor William Glasson AO (Co-Chair), Ophthalmologist, Chairman of Indigenous Rural Eye Services, Head of QLD Oncology Service (QLD)

Dr Siddhartha Baxi, Radiation Oncologist, South West Radiation Oncology, Bunbury (WA)

Ms Janiece Coats, Cancer Survivor and Clinical Nurse, Cancer Care Coordinator, Cancer Services, Cairns Hospital (QLD)

Ms Pauline Deweerd, Director Aboriginal Health, St Vincent's Health Network (NSW)

Professor Gail Garvey, Senior Research Fellow, Menzies School of Health Research (QLD)

Mr Kar Giam, Practice Manager and Chief Radiation Therapist, Alan Walker Cancer Care Centre (NT)

Associate Professor Louis Irving, Respiratory Physician, Royal Melbourne Hospital (Vic)

Dr Rohit Joshi, Consultant, Medical Oncology, Lyell McEwin Hospital (SA)

Professor Dorothy Keefe PSM, Clinical Ambassador, Transforming Health (SA)

Associate Professor Kelvin Kong, Consultant Ear Nose and Throat Surgeon, Hunter ENT (NSW)

Ms Melanie Lane, Cancer Survivor and Senior Aboriginal and Torres Strait Islander Health Worker, Mallee District Aboriginal Services (Vic)

Ms Masita Maher, Aboriginal Community Liaison, Cancer Institute (NSW)

Ms Liela Murison, Indigenous Women's Cancer Coordinator, Screening and Early Detection, Townsville Cancer Centre (QLD)

Associate Professor (Dr) Brad Murphy, Practice Principal, Ashfield Country Practice, Bundaberg (QLD)

Dr Kelly Needham, Radiation Oncology Registrar, Central Coast Cancer Centre, Gosford Hospital (NSW)

Professor Sabe Sabesan, Director, Department of Medical Oncology, Townsville Hospital and Health Services (QLD)

Ms Robyn Sharman, Aboriginal Projects Coordinator, Hume Regional Integrated Cancer Service (Vic)

Mr Grant Smith, Manager/Chief Radiation Therapist, Northern Cancer Service, Launceston General Hospital (Tas)

Ms Josslyn Tully, Chair, the National Aboriginal and Torres Strait Islander Health Worker Association (NATSIHWA) (QLD)

Ms Vicki Wade, Board member, Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) (NSW)

Dr Kali Hayward, President, Australian Indigenous Doctors' Association (SA)

Ms Sophia Wooldridge, Clinical Psychologist, Calvary Mater Newcastle (NSW)

Cancer Australia's Leadership Group on Aboriginal and Torres Strait Islander Cancer Control

Professor Jacinta Elston (Chair), Pro Vice-Chancellor (Indigenous) and Yulendj Indigenous Engagement Unit, Monash University (Vic)

Professor Tom Calma, National Coordinator, Tackling Indigenous Smoking (ACT)

A/Professor Phillip Carson, Chair of External Affairs, Royal Australasian College of Surgeons (NT)

Dr Dawn Casey, Chief Operating Officer, National Aboriginal Community Controlled Health Organisation (NACCHO) (ACT)

Professor Gail Garvey, Senior Research Fellow, Menzies School of Health Research (QLD)

Dr Kali Hayward, President, Australian Indigenous Doctors' Association (SA)

Ms Tanya McGregor, Chair, National Aboriginal and Torres Strait Islander Health Standing Committee (SA)

Ms Sandra Miller, Consumer representative (SA)

Mr Richard Weston, Chair, National Health Leadership Forum (ACT)

Dr Lisa Whop, Clinical Oncology Society of Australia (COSA) (QLD)

Other stakeholders invited to provide feedback

Aboriginal and Torres Strait Islander Community Controlled Health Services (AMS, ACCHS, ACCHOs)

Aboriginal and Torres Strait Islander Higher Education Advisory Council (ATSIHEAC)

Aboriginal Health and Medical Research Council of New South Wales (AH&MRC)

Aboriginal Health Council of South Australia (AHCSA)

Aboriginal Health Council of Western Australia (AHCWA)

Aboriginal Health Service, Tasmania Aboriginal Medical Services Alliance Northern Territory (AMSANT)

Advisory Group on Aboriginal and Torres Strait Islander Statistics

All state and territory health departments Allied Health Professions Australia

Asian-Pacific Hepato-Pancreato-Biliary Association

Australasian Association of Nuclear Medicine Specialists

Australasian College for Emergency Medicine (ACEM)

Australasian Pancreatic Club

Australia and New Zealand Head and Neck Cancer Society

Australia and New Zealand Hepatic, Pancreatic and Biliary Association

Australia and New Zealand Melanoma Trials Group Australian and New Zealand Gastric and Oesophageal Surgery Association

Australian and New Zealand Society of Palliative Care

Australian Bureau of Statistics (ABS) Australian Cancer Consumer Network

Australian Chapter of Palliative Medicine, RACP

Australian College of Nursing (ACN)

Australian College of Rural and Remote Medicine (ACRRM)

Australian Human Rights Commission

Australian Indigenous Doctors Association (AIDA)

Australian Indigenous Health*Info*Net

Australian Institute of Aboriginal and Torres Strait Islander Studies

Australian Institute of Health and Welfare (AIHW)

Australian Institute of Radiography

Australian Medical Association

Australian National University Indigenous Health Unit

Australian New Zealand Gynaecological Oncology Group

Australian Society Gynaecological Oncologists

Bowel Cancer Australia

Brain Tumour Alliance Australia

Breast Cancer Network Australia

Cancer Action Victoria

Cancer Council Australia

Cancer Nurses Society of Australia (CNSA)

Cancer Voices Australia

CanSpeak

CC National Publications Group

Centre for Aboriginal Primary Health Care Training, Education and Research

Charles Darwin University Australian Centre for Indigenous Knowledge and Education

Chris O’Brien Lifehouse

Clinical Oncological Society of Australia (COSA)

Closing the Gap Indigenous Health

Leadership Group

Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)

Cooperative Trials Group for Neuro-Oncology

Department of Education and Training

Dietitians Association of Australia

Edith Cowan University Kurongkurl Katitjin Centre for indigenous Australian Education and Research

First People’s Disability Network (FPDN)

Flinders University Poche Centre for Indigenous health and wellbeing

Gastroenterological Society of Australia

Haematology Society of Australia and New Zealand (HSANZ)

Indigenous Allied Heath Australia

Interventional Radiology Society of Australasia

James Cook University

Kimberley Aboriginal Medical Services Council (KAMSC)

La Trobe University Office of Indigenous Strategy and Education

Leukaemia Foundation

Lowitja Institute

Lung foundation

Medical Oncology Group of Australia (MOGA)

Melanoma Patients Australia

Melbourne Melanoma Project

Menzies School of Health Research

Movember Foundation

National Aboriginal and Torres Strait Islander Legal Services (NATSILS)

National Aboriginal and Torres Strait Islander Women's Alliance (NATSIWA)

National Aboriginal Community Controlled Health organisation (NACCHO)

National Association of Aboriginal and Torres Strait Islander Physiotherapists

National Breast Cancer Foundation

National Centre for Indigenous Excellence (NCIE)

National Congress of Australia's first peoples

National Family Violence Prevention Legal Services (FVPLS) Forum

National Rural Health Alliance

Ovarian Cancer Australia

Palliative Care Australia

Primary Health Networks

Prime Minister's Indigenous Advisory Council

Prostate Cancer Foundation of Australia

Queensland Aboriginal and Islander Health Council (QAIHC)

Royal Australasian College of Dental Surgeons

Royal Australian College ofGeneral Practitioners (RACGP)

Royal Australian College of General Practitioners (RACGP), National Aboriginal & Torres Strait Islander Health Faculty

SNAICC – National Voice for our Children

South Australian Health & Medical Research Institute (SAHMRI)

State and territory BreastScreen services

The Alan Walker Cancer Centre

The Bachelor Institute of Indigenous Tertiary Education

The Department of the Prime Minister and Cabinet (PM&C)

The Healing Foundation

The National Aboriginal and Torres Strait Islander Health Equality Council (NATSIHEC)

The National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID)

The Royal Australasian College of Physicians (RACP)

The Royal Australasian College of Surgeons (RACS)

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)

The Royal Australian and New Zealand College of Psychiatrists (RANZCP)

The Royal Australian and New Zealand College of Radiologists (RANZCR)

The Royal College of Pathologists of Australasia

The University of Adelaide Yaitya Purruna Indigenous Health unit

The University of Melbourne Poche Centre for Indigenous health

The University of Queensland Poche Centre for Indigenous Health

The University of Sydney Poche Centre for Indigenous health

The University of Western Australia Poche Centre for Indigenous Health

The Aboriginal and Torres Strait Islander Health Advisory Committee (ATSIHAC)

University of New South Wales Muru Marri

University of South Australia

Victorian Aboriginal Community Controlled Health Organisation Inc (VACCHO)

Victorian Comprehensive Cancer Centre (VCCC)

Winnunga Nimmityjah Aboriginal Health Service

Appendix A: Case study examples

The Beautiful Shawl Project, co-design and Women's Business

Aboriginal and Torres Strait Islander women participate at lower rates in breast cancer screening programs than non-Indigenous women. Consultation with Aboriginal and Torres Strait Islander women in Victoria about screening found that while many understood the importance of breast screening, they experienced feelings of embarrassment and shame around being naked in front of a stranger. The women suggested a shawl to cover their upper bodies throughout screening.

BreastScreen Victoria, the Victorian Aboriginal Health Service and the Victorian Aboriginal Community Controlled Health Organisation trialled the use of the shawls that were designed to feature artwork by local Aboriginal artists. The success of the project is attributed to being community led and co-designed, and for championing cultural safety on the cancer care pathway.

www.clara.breastscreen.org.au/intranet/documents/11/3800/The_Beautiful_Shawl_Implementation_Model_Apr2022.pdf

Cervical screening self-sampling

Marathon Health's Primary Health Care Nurses (PHCNs) consulted extensively with local organisations and community members across rural and remote regions of New South Wales to establish a pilot nurse-led community engagement model for cervical screening self-sampling. By the model:

- PHCNs established partnerships with Local Aboriginal Land Councils (LALC) as the representative body for Aboriginal people in each community
- each LALC identified a female employee or community member to recruit as the Community Engagement Worker (CEW) for each site
- the CEW role was to engage and recruit women to the program and support them along the self-sampling pathway, with clinical support provided by the PHCN
- once the women completed the self-sample with the support of the PHCN and CEW, the PHCN sent the cervical screening test to the Victorian Cytology Service Foundation to be analysed
- pathology results were returned by mail to the participant, their nominated general practitioner (GP) and the PHCN
- the PHCN followed up with all participants face-to-face or by phone to ensure they received their results and that they understood their meaning, including any follow-up that was required
- women who returned invalid results were provided the option to rescreen.

Eight pilot sites were established; seven had minimal access to female GPs. Over 21 months, self-sampling kits were distributed to 215 never- or under-screened Indigenous women in the region. About 20% tested positive for HPV and referred for a clinician-collected cervical screening test, and some were referred for urgent specialist evaluation. About 92% of the women participating completed an evaluation survey. Almost all welcomed the model. They reported feeling a sense of control over their Women's Business, health and wellbeing. They particularly appreciated the verbal communication of results from the PHCN, as many women could not understand them otherwise.

www.ncbi.nlm.nih.gov/pmc/articles/PMC7212679/

The one stop liver shop

Aboriginal and Torres Strait Islander people, particularly those in the Northern Territory (NT), are significantly disproportionately affected by chronic hepatitis B (CHB) infection. Without detection and appropriate care, about 25% of those living with CHB will die from either liver failure or liver cancer. Aboriginal and Torres Strait Islander people, including those living in remote areas, are more likely to have limited access to appropriate testing, monitoring, treatment and care, including Pharmaceutical Benefits Scheme (PBS)-funded antiviral treatment.

In 2013, one very remote NT community, 500 kilometres from Darwin, pioneered a 'one stop liver shop' to address these inequities. It was based on an innovative service delivery model that has potential application for mobile clinics for other cancers and health areas.

The 'shop team" is made up of:

- a community-based Aboriginal Health Practitioner (AHP) who coordinates four per-year, two-day travelling clinics (including patient appointments)
- a specialist doctor
- a sonographer
- a clinical nurse specialist

They are supported by a range of ultrasound scanning equipment and diagnostic tools.

Around the clinic dates, community awareness raising and uptake is promoted through a 'Hep B Story' app in Yolngu Matha and English. Two community- based educators, as well as the coordinating AHP, have been trained and supported to deliver the education using this app in a culturally safe and respectful way.

The model's effectiveness was evaluated through analysis of 83 patient records.

- 88% were engaged in care, 16% of whom were receiving antiviral treatment.
- Liver function tests were up to date in 71% of patients in 2013, and 88% of patients in 2018.
- Viral load monitoring was up to date for 73% of patients.

Access to screening and scanning was also significantly enhanced through the shop.

The evaluation concluded: "Emphasis must be placed on the importance of the Aboriginal Health Practitioner's role at the centre of the model. For this care model to be sustainable systematic implementation is essential."

www.equityhealthj.biomedcentral.com/articles/10.1186/s12939-020-01180-w

Peter MacCallum Cancer Centre – A welcoming environment

A possum skin cloak, handmade by Aboriginal women who have had cancer, is used at the Peter MacCallum Cancer Centre as a symbol of healing and support for other Aboriginal and Torres Strait Islander people going through cancer treatment and their families. The cloak was made as part of the Breast Cancer Network Australia ‘Culture is Healing’ program, which aims to create culturally appropriate spaces in hospital.

www.canceraustralia.gov.au/sites/default/files/publications/optimal-care-pathway-aboriginal-and-torres-strait-islander-people-cancer-guide/pdf/optimal_care_pathway_for_aboriginal_and_torres_strait_islander_people_with_cancer_the_guide.pdf

Resource list

For patients, families and carers

13YARN

13YARN is an Aboriginal and Torres Strait Islander crisis support line funded by the Australian Government with the support of Lifeline and developed in collaboration with Gayaa Dhuwi (Proud Spirit) Australia. It offers confidential one-on-one over-the-phone yarning opportunity and support with a trained Lifeline Aboriginal and Torres Strait Islander Crisis Supporter for mob who are feeling overwhelmed or having difficulty coping.

- Telephone: 13 YARN (13 92 76)
- Website: www.13yarn.org.au

Aboriginal Interpreter services

Northern Territory:

- Telephone: 1800 334 944
- www.nt.gov.au/community/interpreting-and-translating-services/aboriginal-interpreter-service

South Australia:

- Telephone: (08) 8364 5255

Western Australia:

- Telephone: 1800 330 331

www.aiwaac.org.au

Advance Care Planning

Advance Care Planning Australia provides national advance care planning resources for individuals, families, health professional and service providers. Resources include a national advisory service, information resources, a legal forms hub and education modules.

- Telephone: 1300 208 582
- Website: www.advancecareplanning.org.au/

Angel Flight

Angel Flight Australia is a charitable organisation coordinating free, non-emergency flights and ground transportation so people who live in rural and regional Australia can access the specialist medical treatments they need.

- Telephone: 1300 726 567
- Website: www.angelflight.org.au/

Australasian Lymphology Association

The Australasian Lymphology Association has a number of key resources to assist people in gaining an understanding of lymphoedema and the treatments available for the condition.

- Telephone: 1300 935 332
- Website: www.lymphoedema.org.au/

Australian Cancer Survivorship Centre

The Australian Cancer Survivorship Centre has developed information resources and events to help people move from initial treatment to post treatment and beyond, including those receiving maintenance treatments. While they do not provide clinical advice, they connect with a range of providers to enable improved care.

- Telephone: (03) 8559 6220
- Website: www.petermac.org/cancersurvivorship

Australian Commission on Safety and Quality in Health Care

The Australian Commission on Safety and Quality in Health Care has developed a resource for patients and carers explaining the coordination of care that patients should receive from their health service during cancer treatment. The resource is called *What to expect when receiving medication for cancer care* www.safetyandquality.gov.au/publications-and-resources/resource-library/what-expect-when-receiving-medication-cancer-care-fact-sheet

Beyond Blue

Beyond Blue provides information about depression, anxiety and related disorders, as well as about available treatment and support services.

- Telephone: 1300 22 4636
- Website: www.beyondblue.org.au/

Can Assist

Can Assist provides assistance for people affected by cancer in rural and regional New South Wales, ensuring they have access to cancer treatment and care by providing accommodation, financial assistance and practical support.

- Telephone: 1300 226 277
- Website: www.canassist.org.au/

Cancer Council's Cancer Information and Support Service

Cancer Council is a confidential telephone support service available to anyone affected by cancer. This service acts as a gateway to evidence-based, documented, practical and emotional support available through Cancer Council services and other community organisations. Calls will be answered by a nurse or other oncology professional who can provide information relevant to a patient's or carer's situation. Health professionals can also access this service.

- Telephone: 13 11 20 – Monday to Friday, 9.00 am to 5.00 pm (some states have extended hours)
- Website: About Cancer Council | Cancer Council

Cancer Council's Cancer Connect

Cancer Connect is a free and confidential telephone peer-support service that connects someone who has cancer with a specially trained volunteer who has had a similar cancer experience.

A Connect volunteer can listen with understanding and share their experiences and ways of coping. They can provide practical information, emotional support and hope. Many people newly diagnosed with cancer find this one-to-one support very beneficial.

For more information on Cancer Connect call Cancer Council on 13 11 20.

Canteen

Canteen helps adolescents, young adults and parents to cope with cancer in their family.

Canteen offers individual support services, peer support services and a youth cancer service, as well as books, resources and useful links.

- Telephone: 1800 835 932 to talk to a health professional about information and support for young people, or 1800 226 833 for other enquiries
- Website: www.canteen.org.au/

Carer Gateway

Carer Gateway is an Australian Government program providing free services and support to carers, including:

- in-person and online peer support groups
- tailored support packages to help with accessing planned respite, transport services, and more
- in-person and phone counselling
- in-person and online self-guided coaching
- online skills courses to support your wellbeing and understanding of legal responsibilities relating to the caring role
- access to emergency respite if you suddenly find you can't provide care, for example if you become ill or injured.
    - Telephone: 1800 422 737
    - Website: www.carergateway.gov.au/

Clinical trial information

For a collection of clinical trials available in Australia see the following sources of information:

- Australian clinical trials: www.australianclinicaltrials.gov.au/
- Australian New Zealand Clinical Trials Registry: www.anzctr.org.au
- ClinicalTrials.gov: www.clinicaltrials.gov/

CanEAT pathway

A guide to optimal cancer nutrition for people with cancer, carers and health professionals.

- Website: www.petermac.org/patients-and-carers/health-services-for-cancer-patients/allied-health-services/nutrition-and-dietetics/malnutrition-screening-tool
- Website: Eating well | Cancer Institute NSW

Guides to best cancer care

The short guides help patients, carers and families understand the optimal cancer care that should be provided at each step. They include optimal timeframes within which tests or procedures should be completed, prompt lists to support patients to understand what might happen at each step of their cancer journey and to consider what questions to ask, and provide information to help patients and carers communicate with health professionals.

The guides are located on an interactive web portal, with downloadable PDFs available in multiple languages.

- Website: www.cancer.org.au/cancercareguides

Head to Health

Australian Government website providing mental health support for Aboriginal and Torres Strait Islander people.

- Website: www.headtohealth.gov.au/living-well/support-aboriginal-torres-strait-islander-people

Look Good, Feel Better

A free national community service program, run by the Cancer Patients Foundation, dedicated to teaching cancer patients how to manage the appearance-related side effects caused by treatment for any type of cancer.

- Telephone: 1800 650 960
- Website: www.lgfb.org.au

Legal Aid

The Civil Law Service for Aboriginal Communities (CLSAC) is a team that provides confidential legal help to Aboriginal clients living in regional and remote areas of New South Wales and Aboriginal women in custody.

- Telephone: 1800 793 017 or (02) 9219 5057
- Website: www.legalaid.nsw.gov.au/my-problem-is-about/my-right-as-a/aboriginal-or-torres-strait-islander/civil-law-service-for-aboriginal-communities

Legal Services

There are Aboriginal and/or Torres Strait Islander Legal Services all around Australia:

ACT/NSW
Aboriginal Legal Service NSW/ACT

- Telephone: 1800 765 767 for police and court matters 1800 733 233 for care and protection matters
- Website: www.alsnswact.org.au/

NT
North Australian Aboriginal Justice Agency

- Telephone: 1800 898 251
- Website: www.naaja.org.au/

- QLD
  Aboriginal and Torres Strait Islander Legal Service Queensland

- Telephone: (07) 3025 3888
- Website: www.atsils.org.au/

SA
Aboriginal Legal Rights Movement

- Telephone: 1800 643 222
- Website: www.alrm.org.au/

TAS
Tasmanian Aboriginal Legal Service

- Telephone: 1800 595 162
- Website: www.tals.net.au/

VIC
Victorian Aboriginal Legal Service

- Telephone: 1800 064 865
- Website: www.vals.org.au/

WA
Aboriginal Legal Service of Western Australia

- Telephone: 1800 019 900
- Website: www.als.org.au/

Leukaemia Foundation Patient Transport Program

A free transport program for people with blood cancer-like leukaemia, lymphoma or myeloma.

- Telephone: 1800 620 420
- Website: www.leukaemia.org.au/how-we-can-help/transport-services/

Money Smart

Money Smart is a free Australian Government service that helps Australians take control of their money with free tools, tips and guidance. It also has a section for Indigenous people with money tips and resources. The ASIC Indigenous Help Line gives advice with banking, insurance or other money worries.

- Indigenous Help Line: 1300 365 957
- Website: www.moneysmart.gov.au/

National Debt Helpline

The National Debt Helpline is free, independent and confidential service that provides financial advice to help people tackle their debt problems.

- Telephone: 1800 007 007
- Website: www.ndh.org.au/

Patient Assisted Travel Schemes (PATS)

All states and territories have Patient Assisted Travel Schemes (PATS) to help eligible patients in rural and remote Australia with the costs of travel. These can help you access specialist medical services not available locally.

Rules and amounts vary, but all PATS schemes help cover:

- travel expenses for public transport
- accommodation costs at your destination
- travel expenses and accommodation costs of your eligible support person or carer.
- Website: Fact Sheets | NRHA - National Rural Health Alliance

Quitline

Quitline is a confidential, evidence-based telephone counselling service. Highly trained Quitline counsellors use behaviour change techniques and motivational interviewing over multiple calls to help people plan, make and sustain a quit attempt.

Quitline is a culturally inclusive service for all, and Aboriginal counsellors are also available. Health professionals can refer patients to Quitline online.

- Telephone: 13 7848
- Website: www.quit.org.au/ or the relevant website in your state or territory.

Ronald McDonald House

Ronald McDonald Houses provide a homely and inviting place to stay for parents, guardians, carers and their siblings while their child is undergoing treatment in a nearby hospital.

- Telephone: 1300 307 642
- Website: www.rmhc.org.au/

Rural Health Outreach Fund

The Rural Health Outreach Fund (RHOF) supports outreach initiatives that improve access to medical specialists, general practitioners and allied and other health providers in regional, rural and remote areas of Australia.

- Contact: RHOF@health.gov.au
- Website: www.health.gov.au/our-work/rural-health-outreach-fund

Royal Flying Doctor Service (RFDS)

The RFDS is a national, charitable, health organisation delivering primary health care and 24-hour emergency services for those that live in rural and remote Australia.

- Telephone: 1300 My RFDS (1300 69 7337)
- Website: www.flyingdoctor.org.au/

Yarn Safe

Mental health support for Aboriginal and Torres Strait Islander people under 25 years of age.

- Website: www.headspace.org.au/yarn-safe/

For health providers

Australian Cancer Survivorship Centre

The Australian Cancer Survivorship Centre provides expertise in survivorship care, information, support and education. Its purpose is to support and enable optimal survivorship care.

- Telephone: (03) 8559 6220
- Website: www.petermac.org/patients-and-carers/support-and-wellbeing/life-after-treatment

Australian Commission on Safety and Quality in Health Care

The Australian Commission on Safety and Quality in Health Care has developed a guide for clinicians containing evidence-based strategies to support clinicians to understand and fulfil their responsibilities to cancer patients.

This guide is particularly relevant to Steps 3 to 6 of the optimal care pathway. The guide is titled NSQHS Standards user guide for medication management in cancer care for clinicians

- Website: www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-user-guide-medication-management-cancer-care

Australian Indigenous Health*Info*Net

The Australian Indigenous Health*Info*Net provides support to those working in the Aboriginal and Torres Strait Islander health sector by making research and other knowledge readily accessible.

- Website www.healthinfonet.ecu.edu.au/

Cancer Australia

Information for health providers including guidelines, cancer learnings, cancer guides, reports, resources, videos, posters and pamphlets.

- Website: www.canceraustralia.gov.au/
- Cancer Australia resources for health professionals: www.canceraustralia.gov.au/affected-cancer/atsi/resources-health

Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority.

- Website: www.cancer.org.au/

CanEAT pathway

A guide to optimal cancer nutrition for people with cancer, carers and health professionals.

- Website: www.petermac.org/patients-and-carers/health-services-for-cancer-patients/allied-health-services/nutrition-and-dietetics/malnutrition-screening-tool
- Website: Eating well | Cancer Institute NSW

Cancer Council NSW

Information for health workers to support Aboriginal and Torres Strait Islander people affected by cancer.

- Website: www.aboriginal.cancercouncil.com.au/health-workers/

Consumer's Perspective of the Quality of Care Survey Protocol (2015)

The Consumer's Perspective of the Quality of Care Survey (CPoQC-S) tool has been designed to collect feedback from clients about what they think about the quality of care they are receiving for their ongoing condition. The tool has been specifically designed for use in the remote primary healthcare context but is easily adapted to suit other care delivery contexts.

- Website: www.menzies.edu.au/icms_docs/253219_2016_Release_Consumers_Perspective_Protocol.pdf

Culturally safe communication skills – tips for non-Indigenous health professionals

A free resource with a series of short videos and a key messages tip sheet providing practical advice for cancer care specialists to optimise culturally safe and responsive communication with Aboriginal and Torres Strait Islander patients, their families and carers.

- Website: www.canceraustralia.gov.au/culturally-safe-communication-skills-tips-for-non-Indigenous-health-professionals

eviQ

A clinical information resource providing health professionals with current evidence-based, peer-maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment.

- Website: www.eviq.org.au/

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment.

- Website: www.nhmrc.gov.au/

National best practice guidelines for collecting Indigenous status in health data sets

The Best Practice Guidelines document the recommended national approach for collecting and recording accurate information on the Indigenous status of clients.

- Website: www.aihw.gov.au/reports/indigenous-australians/national-guidelines-collecting-health-data-sets/summary

New South Wales Department of Community Services resource: Working with Aboriginal people and communities – a practice resource

This resource is a guide for all Community Services and relevant non-government organisation (NGO) staff, particularly field staff. It has been developed to improve service delivery to Aboriginal people by providing staff with key facts, and information relevant to working with Aboriginal communities in NSW.

- Website: www.community.nsw.gov.au/__data/assets/pdf_file/0017/321308/working_with_aboriginal.pdf

Our Mob and Cancer

The Our Mob and Cancer website is an Australian website created by Aboriginal and Torres Strait Islander people for Aboriginal and Torres Strait Islander people affected by cancer. It is a central hub of culturally appropriate, evidence- and strengths-based information about cancer for Aboriginal and Torres Strait Islander people, communities and their health professionals. The website contains information for Aboriginal and Torres Strait Islander people and their health professionals about cancer types, prevention, diagnosis, treatment, living with cancer, metastatic disease and finding support.

- Website: www.ourmobandcancer.gov.au/
- Section for health professionals: www.ourmobandcancer.gov.au/for-health-professionals

Yarn for Life

Yarn for Life is a national multiplatform communication campaign aiming to reduce the impact of cancer within Aboriginal and Torres Strait Islander communities by encouraging and normalising conversations about cancer and promoting the importance of early detection. The website contains a number of videos and other resources that discuss a central message: “It’s ok to talk about cancer”.

- Website: yarnforlife.com.au/

Glossary

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

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

Aboriginal Community Controlled Health Services (ACCHS) – are non-government, not-for-profit primary healthcare services initiated and operated by the local Aboriginal community to deliver holistic, comprehensive and culturally responsive health care. ACCHS are incorporated, based in an Aboriginal community, and governed by a majority Aboriginal board, which the local community elects.

Advance care planning – Advance care planning is the process where an individual decides and documents their preferences for their future health care. Advance care planning prepares individuals for a time when they may be unable to communicate important healthcare decisions.

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

Cancer continuum – a person's cancer experience and interactions with the health system, from prevention and early detection, initial presentation, diagnosis, treatment, survivorship and/or end-of-life 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.

Co-design – brings professionals and end-users together to design new services, resources and policies. Applied to policy, this means enabling or empowering people affected by a policy issue to contribute to its solution.

Co-design with Aboriginal and Torres Strait Islander people is fundamental to achieving change across the health system and to achieve better outcomes. Key principles and best practices for co-design in health with First Nations Australians include First Nations leadership, culturally grounded approach, respect, benefit to community, inclusive partnerships and transparency and evaluation.

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 – a set of behaviours, attitudes and policies that enable a system, service or individual to deliver 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.

Cultural safety – identifies that health consumers are safest when clinicians have considered power relations, cultural differences and patients' rights. Culturally safe practice is the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive health care free of racism. Cultural safety is defined not by the clinician but by the health consumer's experience – the individual's experience of the care they are given and their ability to access services and to raise concerns.

For Aboriginal and Torres Strait Islander people cultural safety is determined by Aboriginal and Torres Strait Islander individuals, families and communities.

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

End-of-life care – is the last of seven steps of the cancer continuum as set out in the optimal care pathways.

This step focuses on maintaining a patient's quality of life and meeting their health and supportive care needs as they approach the end of life, as well as the needs of their family and carers.

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

Health literacy – the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and to take appropriate action.

Health professional – a term used in this pathway to refer to a person involved in providing health care including doctors, nurses, psychologists, oncologists, Aboriginal and/or 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 cancer care. Medical, nursing and allied health professionals involved in a patient's treatment consider all treatment options and personal preferences of the patient, and collaboratively develop an individual care plan that best meets the needs of that patient.

Palliative care – is person- and family-centred care provided for a person with an active, progressive, advanced disease with little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life. Prevention and relief of suffering is provided through early identification and assessment and treatment of pain and other problems such as physical, psychosocial and spiritual concerns.

Patient-reported experience measures (PREMs) – are used to obtain patients' views and observations on aspects of healthcare services they have received. Patient experience data are collected for specific services and then relayed to service providers to instigate improvements in patient services.

Patient-reported outcome measures (PROMs) – measure aspects of a person's health status such as symptoms, quality of life and needs and are collected directly from patients either online, via a smartphone or through paper-based means. Collecting PROMs, and then instigating an appropriate clinical response, has been shown to prolong survival, reduce health system use and improve patients' quality of life. Health services should ensure well-defined, age-appropriate PROMs validated within this cohort are considered to inform optimal care.

Place-based approaches – target the specific circumstances of a place and engage with local people for the development and implementation of programs, services or policies that will have the greatest impact in identifying and responding to the unique needs of the local community. Place-based approaches are characterised by collaboration, partnership, co-design and shared accountability with community.

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.

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.

Survivorship – refers to the process of living with, though, and beyond cancer. By this definition, cancer survivorship begins at diagnosis. It includes people who continue to have treatment to either reduce risk of recurrence or to manage chronic disease and includes the longer-term impacts of cancer treatment on people affected by cancer.

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". Recent studies have identified that Aboriginal and Torres Strait Islander traditional medicine and healing offers a range of benefits for patients, including positive health outcomes, calming effects and improved community trust of mainstream medicine and health services. For these reasons, incorporation of Aboriginal and Torres Strait Islander traditional medicine and healing should be encouraged and supported, wherever practical.

Trauma-aware, healing-informed – Trauma-aware, healing-informed practice is a strengths-based approach to healing that is based on an understanding of, and responsiveness to, the impacts of trauma. It emphasises physical, psychological and emotional safety for people seeking help and for the helpers. It also creates opportunities for people affected by trauma to rebuild a sense of control and empowerment.

This practice recognises the prevalence of trauma and is sensitive to, and informed by, the impacts of trauma on the wellbeing of individuals and communities.

Unconscious bias – is how a person's culture, values and motivations influence their practice.

Voluntary assisted dying – refers to the assistance provided to a person by a health practitioner to end their life. 'Voluntary' indicates that the practice is a voluntary choice of the person, and that they are competent (have capacity) to decide to access voluntary assisted dying.

References

Anderson K, Diaz A, Parikh D, Garvey G 2021, 'Accessibility of cancer treatment services for Indigenous Australians in the Northern Territory: perspectives of patients and care providers', *BMC Health Services Research*, vol. 21, p. 95, doi: 10.1186/s12913-021-06066-3.

Anderson K, Gall A, Butler T, Ngampromwongse K, Hector D, Turnbull S, et al. 2023, 'Development of Key Principles and Best Practices for Co-Design in Health with First Nations Australians', *International Journal of Environmental Research and Public Health*, vol. 20, no. 1, p. 147, doi.org/10.3390/ijerph20010147.

Arthur L, Rolan P 2019, 'A systematic review of western medicine's understanding of pain experience, expression, assessment, and management for Australian Aboriginal and Torres Strait Islander Peoples', *Pain Reports*, vol. 4, no. 6, e764, doi: 10.1097/PR9.0000000000000764.

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

Australian Adult Cancer Pain Management Guideline Working Party 2019, Cancer Council Australia, *Cancer Pain Management in Adults*, viewed 01 November 2023, www.cancer.org.au/assets/pdf/archived-cancer-pain-management-in-adults-guidelines-19-july-2019

Australian Commission on Safety and Quality in Health Care (ACSQH) 2024, *Principles of Care*, viewed 01 November 2023, Person-centred care | Australian Commission on Safety and Quality in Health Care

Australian Government, *Australian Telehealth Program*, viewed 01 November 2023, www.australianteletrialprogram.com.au/

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

Australian Health Practitioner Regulation Agency (AHPRA) 2023, Shared Code of conduct principles, viewed 01 November 2023, www.ahpra.gov.au/Resources/Code-of-conduct/Resources-to-help-health-practitioners/Shared-Code-of-conduct-principles.aspx#:~:text=Respectful%20and%20culturally%20safe%20practice%20for%20all&text=Respectful%2C%20culturally%20safe%20practice%20requires,families%2C%20the%20community%20and%20colleagues.

Australian Human Rights Commission, *Right to self-determination*, viewed 01 November 2023, www.humanrights.gov.au/our-work/rights-and-freedoms/right-self-determination

Australian Indigenous HealthInfoNet 2024., Trauma, Edith Cowan University, Sydney viewed 26 June 2024, www.healthinfonet.ecu.edu.au/learn/health-topics/healing/trauma/

Australian Institute of Health and Welfare (AIHW) 2018, *Cancer in Aboriginal & Torres Strait Islander people of Australia*, AIHW, Canberra, viewed 01 November 2023, www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians/contents/incidence

Australian Institute of Health and Welfare (AIHW) 2021, *Cancer in Australia 2021*, Cancer series no. 133. Cat. no. CAN 144, AIHW, Canberra.

Australian Institute of Health and Welfare (AIHW) 2024, *Aboriginal and Torres Strait Islander Health Performance Framework: summary report*, March 2024. AIHW, Canberra, viewed 15 May 2024, www.indigenoushpf.gov.au/report-overview/overview/summary-report.

Australian Institute of Heath and Welfare (AIHW) 2023a, *Profile of First Nations people,* AIHW, Canberra, viewed 01 November 2023, www.aihw.gov.au/reports/australias-welfare/profile-of-indigenous-australians.

Australian Institute of Health and Welfare (AIHW) 2023b, *Ear and hearing health of Aboriginal and Torres Strait Islander people 2023*, catalogue number IHW 282, AIHW, Australian Government, Canberra.

Australian Institute of Health and Welfare (AIHW) 2023c, *Cultural safety in health care for Indigenous Australians: monitoring framework,* AIHW, Canberra, viewed 01 November 2023, www.aihw.gov.au/reports/indigenous-australians/cultural-safety-health-care-framework/contents/about

Australian Institute of Health and Welfare (AIHW), Fact Sheet: Are you of Aboriginal or Torres Strait Islander Origin?, AIHW, Canberra, viewed 15 May 2024, www.aihw.gov.au/getmedia/6832e411-bb74-49e9-aa8e-5fdf0c20f2b8/patient-fact-sheet.pdf.aspx

Australian Institute of Health and Welfare (AIHW) and National Indigenous Australians Agency (NIAA) 2023a, *Aboriginal and Torres Strait Islander Health Performance Framework*, '1.08 Cancer', viewed 01 November 2023, www.indigenoushpf.gov.au/measures/1-08-cancer

Australian Institute of Health and Welfare (AIHW) and National Indigenous Australians Agency (NIAA) 2023b, *Aboriginal and Torres Strait Islander Health Performance Framework*, '3.14 Access to services compared with need', viewed 01 November 2023, www.indigenoushpf.gov.au/measures/3-14-access-services-compared-with-need

Australian Institute of Health and Welfare (AIHW) and National Indigenous Australians Agency (NIAA) 2023c, *Aboriginal and Torres Strait Islander Health Performance Framework*, '3.04 Early Detection and Early Treatment', viewed 01 November 2023, www.indigenoushpf.gov.au/Measures/3-04-Early-detection-early-treatment

Australian Institute of Health and Welfare (AIHW) and National Indigenous Australians Agency (NIAA) 2023d, *Aboriginal and Torres Strait Islander Health Performance Framework*, '1.09 Diabetes', viewed 01 November 2023, www.indigenoushpf.gov.au/measures/1-09-diabetes

Australian Institute of Health and Welfare (AIHW) and National Indigenous Australians Agency (NIAA) 2023e, *Aboriginal and Torres Strait Islander Health Performance Framework*, '3.08 Cultural competency', viewed 01 November 2023, www.indigenoushpf.gov.au/measures/3-08-cultural-competency

Australian Institute of Health and Welfare (AIHW) and National Indigenous Australians Agency (NIAA) 2023f, *Aboriginal and Torres Strait Islander Health Performance Framework*, '2.15 Tobacco Use', viewed 01 November 2023, www.indigenoushpf.gov.au/measures/2-15-tobacco-use

Bailie J, Matthews V, Laycock A, Schultz R, Bailie R 2016, 'Preventive Health Care for Aboriginal and Torres Strait Islander People: Final Report'. ESP Project: Priority Evidence-Practice Gaps and Stakeholder Views on Barriers and Strategies for Improvement, Menzies School of Health Research, Darwin.

Bainbridge R, McCalman J, Clifford A, et al. 2015. *Cultural competency in the delivery of health services for Indigenous people*, Issues paper no. 13. Produced for the Closing the Gap Clearinghouse. AIHW, Canberra & AIFS, Melbourne.

Banham D, Roder D, Thompson S, Williamson A, Bray F, Currow D 2023, 'The effect of general practice contact on cancer stage at diagnosis in Aboriginal and non-Aboriginal residents of New South Wales', *Cancer Causes & Control*, vol. 34, no. 10, pp. 909–926, doi: 10.1007/s10552-023-01727-6.

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

Butler T, Anderson K, Condon J, Garvey G, Brotherton J, Cunningham J, et al. 2020, 'Indigenous Australian women's experiences of participation in cervical screening'. *PLOS ONE*, vol. 15, no. 6, e0234536, doi: 10.1371/journal.pone.0234536.

Butler T, Lee N, Anderson K, Brotherton J, Cunningham J, Condon J, et al. 2022a, 'Under-screened Aboriginal and Torres Strait Islander women's perspectives on cervical screening', *PLOS ONE*, vol. 17, no. 8, e0271658, doi: 10.1371/journal.pone.0271658.

Butler T, Gall A, Garvey G, Ngampromwongse K, Hector D, Turnbull S, et al. 2022b, 'A Comprehensive Review of Optimal Approaches to Co-Design in Health with First Nations Australians'. *International Journal of Environmental Research and Public Health*, vol. 19, no. 23, p. 16166, doi: 10.3390/ijerph192316166. PMID: 36498237; PMCID: PMC9735487.

Butler T, Smith B, Pilatti K, Brown B, Anderson K, Morris B, et al. 2023, 'Fear of Cancer Recurrence among Aboriginal and Torres Strait Islander Women Diagnosed with Breast Cancer', *Current Oncology*, vol. 30, no, 3, pp. 2900–2915, doi: 10.3390/curroncol30030222.

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

Cancer Australia 2015, *National Aboriginal and Torres Strait Islander cancer framework*, Cancer Australia, Surry Hills, viewed 24 August 2017, National Aboriginal and Torres Strait Islander Cancer Framework | Cancer Australia

Cancer Australia 2018, *Cancer Supportive Care Principles*, Cancer Australia, Surry Hills, viewed 01 November 2023, www.cnsa.org.au/documents/item/1706

Cancer Australia 2020, *A Guide to Implementing the Optimal care pathway for Aboriginal and Torres Strait Islander People with Cancer*, Cancer Australia, Surry Hills, viewed 01 November 2023, www.canceraustralia.gov.au/sites/default/files/publications/optimal-care-pathway-aboriginal-and-torres-strait-islander-people-cancer-guide/pdf/optimal_care_pathway_for_aboriginal_and_torres_strait_islander_people_with_cancer_the_guide.pdf.

Cancer Australia 2023, *Australian Cancer Plan (Summary)*, Cancer Australia, Surry Hills, viewed 01 November 2023, www.canceraustralia.gov.au/australian-cancer-plan.

Cancer Australia 2024a, *Principles of multidisciplinary care*, Cancer Australia, Surry Hills, viewed 01 November 2023, www.canceraustralia.gov.au/clinicians-hub/multidisciplinary-care/all-about-multidisciplinary-care/principles-multidisciplinary-care

Cancer Australia 2024b, *Planning a Multidisciplinary Team Meeting*, Cancer Australia, Surry Hills, viewed 01 November 2023, www.canceraustralia.gov.au/clinicians-hub/multidisciplinary-care/all-about-multidisciplinary-care/planning-multidisciplinary-care-meeting

Cancer Australia 2024c, *Shared cancer follow-up and survivorship care*, Cancer Australia, Surry Hills, viewed 01 November 2023, www.canceraustralia.gov.au/clinical-best-practice/shared-follow-care

Cancer Council 2020, *End-of-life care*, Cancer Council, Australia, viewed 01 November 2023, www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment/end-of-life-care

Christie V, Green D, Skinner J, Riley L, O'Shea R, Littlejohn K, et al. 2023a, 'Everyone needs a Deb: what Australian Indigenous women say about breast cancer screening and treatment services', *BMC Health Services Research*, vol. 23, p. 672, doi: 10.1186/s12913-023-09633-y.

Christie V, Riley L, Green D, Snook K, Henningham M, Rambaldini B, et al. 2023b, 'Does breast cancer policy meet the needs of Aboriginal and Torres Strait Islander women in Australia? a review', *International Journal for Equity in Health*, vol. 22, no. 1, p. 129, doi: 10.1186/s12939-023-01941-3.

Chynoweth J, McCambridge M, Zorbas H, Elston J, Thomas R, Glasson W, et al. 2020, 'Optimal Cancer Care for Aboriginal and Torres Strait Islander People: A Shared Approach to System Level Change', *JCO Global Oncology*, vol. 6, pp.108–114, doi: 10.1200/JGO.19.00076.

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

Clinical Oncology Society of Australia (COSA) 2015, *COSA Guidelines for Teleoncology*, COSA, Sydney.

Clinical Oncology Society of Australia (COSA) 2016, *Australasian Tele-trial Model Access to clinical trials closer to home using tele-health. A National Guide for Implementation*, COSA, Sydney.

Coalition of Aboriginal and Torres Strait Islander Peak Organisations and Australian Governments 2020, *National Agreement on Closing the Gap*, Australian Government, Canberra.

Commonwealth of Australia 2017, *National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing*, Department of the Prime Minister and Cabinet, Canberra.

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

Cramb S, Whop L, Garvey G, Baade P 2023, 'Cancer survival differentials for Aboriginal and Torres Strait Islander peoples in Queensland: the impact of remoteness', *Cancer Causes & Control*, vol. 34, no. 1, pp. 13–22, doi: 10.1007/s10552-022-01643-1.

Cubillo C 2021, 'Trauma-informed care: Culturally responsive practice working with Aboriginal and Torres Strait Islander communities', *InPsych*, vol. 43, no. 3, viewed 01 November 2023, www.psychology.org.au/for-members/publications/inpsych/2021/august-special-issue-3/trauma-informed-care.

Cunningham J 2002, 'Diagnostic and therapeutic procedures among Australian hospital patients identified as Indigenous', *Medical Journal of Australia*, vol. 176, no. 2, pp. 58–62, doi: 10.5694/j.1326-5377.2002.tb04284.x.

Cunningham J, Garvey G 2021, 'Are there systematic barriers to participation in cancer treatment trials by Aboriginal and Torres Strait Islander cancer patients in Australia?', Australian and New Zealand Journal of Public Health, vol. 45, no. 1, pp. 39–45, doi 10.1111/1753-6405.13059

Dasgupta P, Garvey G, Baade P 2022, 'Quantifying the number of deaths among Aboriginal and Torres Strait Islander cancer patients that could be avoided by removing survival inequalities, Australia 2005–2016', *PLOS ONE*, vol. 17, no. 8:e0273244, doi.org/10.1371/journal.pone.0273244.

de Witt A, Cunningham F, Bailie R, Percival N, Adams J, Valery P 2018, 'It's Just Presence, the Contributions of Aboriginal and Torres Strait Islander Health Professionals in Cancer Care in Queensland', *Frontiers in Public Health*, vol. 6, p. 344, doi:10.3389/fpubh.2018.00344.

de Witt A, Matthews V, Bailie R, Valery P, Adams J, Garvey G, et al. 2022, 'Aboriginal and Torres Strait Islander patients' cancer care pathways in Queensland: Insights from health professionals', *Health Promotion Journal of Australia*, vol. 33, no. 3, pp. 701–710, doi: 10.1002/hpja.556.

Department of Health 2017, *My life my lead. Opportunities for strengthening approaches to the social determinants and cultural determinants of Indigenous health: report on the national consultations*, December 2017, Commonwealth of Australia, Canberra, viewed 13 February 2018, www.health.gov.au/resources/publications/my-life-my-lead-report-on-the-national-consultations.

Department of Health and Aged Care (DoHAC) 2022a, *Australian Immunisation Handbook*, viewed 01 November 2023, www.immunisationhandbook.health.gov.au/contents/about-the-handbook

Department of Health and Aged Care (DoHAC) 2022b, *About Immunisation*, viewed 01 November 2023, www.immunisationhandbook.health.gov.au/contents/about-the-handbook.

Department of Health and Aged Care (DoHAC) 2022c, *Advance Care Planning*, viewed 01 November 2023, www.health.gov.au/topics/palliative-care/planning-your-palliative-care/advance-care-planning

Department of Health and Aged Care (DoHAC) a, *BreastScreen Australia Program*, viewed 15 May 2024, www.health.gov.au/our-work/breastscreen-australia-program

Department of Health and Aged Care (DoHAC) b, *National Bowel Screening Program*, viewed 15 May 2024, www.health.gov.au/our-work/national-bowel-cancer-screening-program.

Department of Health and Aged Care (DoHAC)c, *National Cervical Screening Program*, viewed 15 May 2024, www.health.gov.au/our-work/national-cervical-screening-program

Department of Health and Aged Care (DoHAC) 2023, *First Nations people and smoking, vaping and tobacco,* viewed 1 November 2023, www.health.gov.au/topics/smoking-vaping-and-tobacco/audiences/first-nations#:~:text=A%20study%20from%202017%20found,from%20the%20harms%20of%20vaping

Durey A, McEvoy S, Swift-Otero V, Taylor K, Katzenellenbogen J, Bassarab D 2016, 'Improving healthcare for Aboriginal Australians through effective engagement between community and health services', *BMC Health Services Research*, vol. 16, p. 224, doi.org/10.1186/s12913-016-1497-0.

Dutton T, Marjoram J, Burgess S, Montgomery L, Vail A, Callan A, et al. 2020, 'Uptake and acceptability of human papillomavirus self-sampling in rural and remote Aboriginal communities: evaluation of a nurse-led community engagement model', *BMC Health Services Research*, vol. 20, p. 398.

Gall A, Leske S, Adams J, Matthews V, Anderson K, Lawler S, et al. 2018, 'Traditional and Complementary Medicine Use Among Indigenous Cancer Patients in Australia, Canada, New Zealand, and the United States: A Systematic Review', *Integrative Cancer Therapies*, vol. 17, no. 3, pp. 568–581, doi: 10.1177/1534735418775821.

Gall A, Andersen K, Adams J, Matthews V, Garvey G 2019, 'An exploration of healthcare providers' experiences and perspectives of Traditional and complementary medicine usage and disclosure by Indigenous cancer patients', *BMC Complementary and Alternative Medicine*, vol. 19, p. 259, doi.org/10.1186/s12906-019-2665-7.

Garvey G, Beesley V, Janda M, Jacka C, Green A, O'Rourke P, et al. 2012, 'The development of a supportive care needs assessment tool for Indigenous people with cancer', *BMC Cancer*, vol. 12, p. 300, doi.org/10.1186/1471-2407-12-300.

Garvey G, Beesley VL, Janda M, O'Rourke P, He V, Hawkes A, et al. 2015, 'Psychometric properties of an Australian supportive care needs assessment tool for indigenous patients with cancer', *Cancer*, vol. 121, no. 17, pp. 3018–3026, doi: 10.1002/cncr.29433.

Giovannucci E, Harlan D, Archer M, Bergenstal R, Gapstur S, Habel L, et al. 2010,. 'Diabetes and cancer: a consensus report', *Diabetes Care*, vol. 33, no. 7, pp.1674–1685, doi: 10.2337/dc10-0666.

Green M, Cunningham J, Anderson K, Griffiths K, Garvey G 2021, ‘Measuring cancer care experiences of Aboriginal and Torres Strait Islander people in Australia: Trial of a new approach that privileges patient voices’. Patient Experience Journal, vol. 8, no. 2, pp. 43–57, doi: 10.35680/2372-0247.1585.

Hla T, Bukulatjpi S, Binks P, Gurruwiwi G, Dhurrkay R, Davies J 2020, ‘A "one stop liver shop" approach improves the cascade-of-care for Aboriginal and Torres Strait Islander Australians living with chronic hepatitis B in the Northern Territory of Australia: results of a novel care delivery model’, *International Journal for Equity in Health*, vol. 19, pp. 64, doi: 10.1186/s12939-020-01180-w.

Jaenke R, Butler T, Condon J, Garvey G, Brotherton J, Cunningham J, et al. 2021, ‘Health care provider perspectives on cervical screening for Aboriginal and Torres Strait Islander women: a qualitative study’, *Australian and New Zealand Journal of Public Health*, vol. 45, no. 2, pp.150–157, doi: 10.1111/1753-6405.13084.

Lethborg C, Halatanu F, Mason T, Posenelli S, Cleak H, Braddy L 2022, ’Culturally Informed, Codesigned, Supportive Care for Aboriginal and Torres Strait Islander People With Cancer and Their Families’, *Australian Social Work*, vol. 75, no. 2, pp.165–117, doi: 10.1080/0312407X.2021.1916050.

Lew J, Feletto E, Worthington J, Roder D, Canuto K, Miller C, et al. 2022, ‘The potential for tailored screening to reduce bowel cancer mortality for Aboriginal and Torres Strait Islander peoples in Australia: Modelling study’, *Journal of Cancer Policy*, vol. 32, p. 100325, doi: 10.1016/j.jcpo.2022.100325.

Li M, Roder D, McDermott R 2018, ‘Diabetes and smoking as predictors of cancer in Indigenous adults from rural and remote communities of North Queensland – A 15-year follow up study’, *International Journal of Cancer*, vol. 143, no. 5, pp. 1054–1106, doi: 10.1002/ijc.31403.

Lockwood L, Ju X, Sethi S, Hedges J, Jamieson L 2024, ‘Knowledge and Awareness of HPV, the HPV Vaccine and Cancer-Related HPV Types among Indigenous Australians’, *International Journal of Environmental Research and Public Health*, vol. 21, no. 3, pp. 307, doi: 10.3390/ijerph21030307.

Luke J, Dalach P, Tuer L, Savarirayan R, Ferdinand A, McGaughran J, et al. 2022, ‘Investigating disparity in access to Australian clinical genetic health services for Aboriginal and Torres Strait Islander people’, *Nature Communications*, vol. 13, no. 1, p. 4966, doi: 10.1038/s41467-022-32707-0.

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

Meiklejohn J, Arley B, Bailie R, Adams J, Garvey G, Martin J, et al. 2018, ‘Community-identified recommendations to enhance cancer survivorship for Aboriginal and Torres Strait Islander people’, *Australian Journal of Primary Health*, vol. 24, issue 3, pp. 233–240, doi: 10.1071/PY17127.

Meiklejohn J, Arley B, Pratt G, Valery P, Bernardes C 2019, 'We just don't talk about it': Aboriginal and Torres Strait Islander peoples' perceptions of cancer in regional Queensland’, *Rural Remote Health*, vol. 19, no. 2, p. 4789, doi: 10.22605/RRH4789.

Menzies School of Health Research (Menzies) 2020, 'National Indigenous Bowel Screening Pilot' Final Report, October 2020, viewed 01 November 2023, www.health.gov.au/sites/default/files/documents/2021/06/final-report-on-the-national-indigenous-bowel-screening-pilot.pdf

Mooi J, Whop L, Valery P, Sabesan S 2012, 'Teleoncology for Indigenous Patients: The Responses of Patients and Health Workers' *Australian Journal of Rural Health*, vol. 20, pp. 265–269, www.doi.org/10.1111/j.1440-1584.2012.01302.x

National Aboriginal Community Controlled Health Organisation (NACCHO) 2022, *Aboriginal Community Controlled Health Organisations (ACCHOs)*, viewed 01 November 2023, www.naccho.org.au/acchos/

National Aboriginal Community Controlled Health Organisation (NACCHO) 2023, *Aboriginal and Torres Strait Islander Cancer Plan*, NACCHO, Canberra.

Nasir B, Ryan E, Black E, Kisely S, Gill N, Beccaria G, et al. 2021, 'The risk of common mental disorders in Indigenous Australians experiencing traumatic life events', *British Journal of Psychiatry Open*, vol. 8, no. 1, e8, doi: 10.1192/bjo.2021.1063.

National Aboriginal and Torres Strait Islander Health Workers Association (NATSIHWA) 2017, *Cultural safety framework*, viewed 01 November 2023 www.naatsihwp.org.au/sites/default/files/natsihwa-cultural_safety-framework_summary.pdf

National Health and Medical Research Council (NMHRC) 2018, *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*, Commonwealth of Australia, Canberra, viewed 24 August 2017, www.nhmrc.gov.au/about-us/resources/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities#block-views-block-file-attachments-content-block-1

National Cancer Control Indicators (NCCI) 2022, *Aboriginal and Torres Strait Islander Cancer Control Indicators, Hepatitis B immunisation*, viewed 01 November 2023, www.ncci.canceraustralia.gov.au/screening-and-immunisation/immunisation/hepatitis-b-immunisation

National Cancer Control Indicators (NCCI) 2024, *Palliative Care*, viewed 01 November 2023, www.ncci.canceraustralia.gov.au/treatment-and-support/palliative-care

National Safety and Quality Health Service (NSQHS) Standards 2020, *Identifying Aboriginal and Torres Strait Islander people* Factsheet, viewed 15 May 2024, www.safetyandquality.gov.au/sites/default/files/2020-07/fact_sheet_-_identifying_aboriginal_andor_torres_strait_islander_people_july_2020.pdf

Olver I, Gunn KM, Chong A, Knott V, Spronk K, Cominos N, et al. 2022, 'Communicating cancer and its treatment to Australian Aboriginal and Torres Strait Islander patients with cancer: a qualitative study', *Support Care Cancer*, vol. 30, no. 1, pp. 431–438, doi: 10.1007/s00520-021-06430-3.

Peppercorn J, Weeks J, Cook F, Joffe S 2004, ‘Comparison of outcomes in cancer patients treated within and outside clinical trials: conceptual framework and structured review’, Lancet, vol. 363, no. 9405, pp. 263–270, doi: 10.1016/S0140-6736(03)15383-4.

Ristevski E, Thompson S, Kingaby S, Nightingale C, Iddawela M 2020, ‘Understanding Aboriginal Peoples’ Cultural and Family Connections Can Help Inform the Development of Culturally Appropriate Cancer Survivorship Models of Care’, JCO Global Oncology, vol. 6, pp. 124–132, doi: 10.1200/JGO.19.00109.

Ristevski E, Ludwick T, Leach M, Thomspon S, Iddawela M, Pryce M, et al. 2022, ‘Implementing Optimal Care Pathways for Aboriginal and Torres Strait Islander People with Cancer: A Survey of Rural Health Professionals' Self-Rated Learning Needs’, *International Journal of Integrated Care*, vol. 22, no. 1, p. 27, doi: 10.5334/ijic.6028.

Sanjida S, Garvey G, Ward J, Bainbridge R, Shakeshaft A, Hadikusumo S, et al. 2022, ‘Indigenous Australians' Experiences of Cancer Care: A Narrative Literature Review’ *International Journal of Environmental Research and Public Health*, vol. 19, no. 24, p. 16947, doi: 10.3390/ijerph192416947.

Sargis R, Simmons R 2019, ‘Environmental neglect: endocrine disruptors as underappreciated but potentially modifiable diabetes risk factors’ *Diabetologia* vol. 62, no. 10, pp. 1811–1822, doi: 10.1007/s00125-019-4940-z.

Shay M 2021, ‘Extending the yarning yarn: Collaborative Yarning Methodology for ethical Indigenist education research’, *Australian Journal of Indigenous Education*, vol. 50, no.1, pp. 62–70, www.doi.org/10.1017/jie.2018.25.

Scott B 2021, ‘Multidisciplinary Team Approach in Cancer Care: A Review of The Latest Advancements’, *EMJ Oncology*, vol. 9, no. 9.

Sjoquist K, Zalcberg J 2013, ‘Clinical trials – advancing cancer care’, *Cancer Forum*, vol. 37, no. 1, pp. 80–88,

Taylor E, Haigh M, Shahid S, Garvey G, Cunningham J, Thompson S 2018, ‘Cancer Services and Their Initiatives to Improve the Care of Indigenous Australians’, *International Journal of Environmental Research and Public Health*, vol. 15, no. 4, p. 717, doi: 10.3390/ijerph15040717.

Tapia K, Garvey G, McEntee M,Rickard M, Lydiard L, Brennan P 2019, ‘Breast screening attendance of Aboriginal and Torres Strait Islander women in the Northern Territory of Australia’, *Australian and New Zealand Journal of Public Health*, vol. 43, no. 4, pp. 334–339, doi: 10.1111/1753-6405.12917.

Taylor V, Lyford M, Holloway M, Parsons L, Mason T, Sabesan S, et al. 2021, ‘"The support has been brilliant": experiences of Aboriginal and Torres Strait Islander patients attending two high performing cancer services’, *BMC Health Services Research*, vol. 21, p. 493, doi: 10.1186/s12913-021-06535-9.

Thewes B, Davis E, Girgis A, Valery PC, Giam K, Hocking A, et al. 2016, ‘Routine screening of Indigenous cancer patients’ unmet support needs: a qualitative study of patient and clinician attitudes’, *International Journal for Equity in Health*, vol. 15, no. 90, pp 1–12.

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

Valery P, Bernardes C, Beesley V, Hawkes A, Baade P, Garvey G 2017, 'Unmet supportive care needs of Australian Aboriginal and Torres Strait Islanders with cancer: a prospective, longitudinal study', *Support Care in Cancer*, vol. 25, no. 3, pp. 869–877.

Whop L, Butler T, Lee N, Cunningham J, Garvey G, Anderson K, et al. 2022, 'Aboriginal and Torres Strait Islander women's views of cervical screening by self-collection: a qualitative study', *Australian and New Zealand Journal of Public Health*, vol. 46, no. 2, pp.161–169, doi: 10.1111/1753-6405.13201.

Williams R 1999, 'Cultural safety – What does it mean for our work practice?' *Australian and New Zealand Journal of Public Health*, no. 23(2), pp. 213–214, doi.org/10.1111/j.1467-842X.1999.tb01240.x

World Health Organization (WHO) 2024, *Cancer: Prevention*, viewed 01 November 2023, www.who.int/health-topics/cancer#tab=tab_2

Zon R, Kennedy E, Adelson K, Blau S, Dickson N, Gill D, et al. 2021, 'Telehealth in Oncology: ASCO Standards and Practice Recommendations', *JCO Oncology Practice*, vol. 17, no. 9, pp. 546–564, www.doi.org/10.1200/OP.21.00438

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

Artist: Jordan Lovegrove, Ngarrindjeri, Dreamtime Creative, www.dreamtimecreative.com.au.