Overview of supporting module six: cancer care for Aboriginal and Torres Strait Islander peoples

Viewers are advised that the following resource contains images, voices and references to deceased people, which could distress or bring sadness, particularly to Aboriginal and Torres Strait Islander peoples.

The resource contains three sections:

1. **Section one:** Epidemiology provides an overview of the epidemiology of cancer in Indigenous populations, looks at cultural factors affecting cancer control in Indigenous communities, and discusses health and health policy for Indigenous Australians.

2. **Section two:** Constructs of cultural safety presents information on cultural safety and respect, effective communication, and describes a number of characteristics unique to Indigenous cultures. It reviews factors contributing to the inequalities of cancer outcomes for Indigenous people and provides a cultural appraisal framework.

3. **Section three:** Nursing care for Indigenous people with cancer examines the ability of the Specialist Cancer Nurse (SCN) to recognise factors that influence Indigenous peoples' attitudes toward cancer, and use cancer prevention programs and other resources developed for Indigenous people. It examines nursing interventions to meet the health needs of Indigenous people affected by cancer.

The resource includes a series of stories to help you apply your understanding and develop effective nursing responses for Indigenous people affected by cancer.

It is recommended that you complete the sections and their related activities in order. This is because each section and each activity includes information that will help you complete the sections and activities that follow.

Learning activities

At times, you will have learning activities to complete. Click on the learning activities button and a list of questions will pop up. The questions will relate to the content you've just read or the video you've just watched.

Videos

Each section contains videos. You can watch the clips when prompted throughout the resource or at any time by clicking on the video icon in the right-side menu.

Suggested citation:

Cancer Australia. (2017) National Cancer Education Project (EdCaN) supporting module six, version 1.4. Retrieved from: http://edcan.canceraustralia.com.au/edcan-learning-resources/supporting-resources/aboriginal-and-torres-strait-islander-peoples

Aim

This resource aims to facilitate the development of competencies that reflect the role of the SCN when working collaboratively with Indigenous people to redress inequities in the burden of cancer for this population. Learning activities aim to develop an SCN's ability to provide culturally safe care when responding to the needs of Indigenous Australians at risk of or affected by cancer.

Rationale

Aboriginal and Torres Strait Islanders are Australia's Indigenous peoples and make up approximately 3% of the total Australian population.[1] In 2011, the Indigenous population of 669,900 peoples* comprised those that identified as being of Aboriginal and / or Torres Strait Islander origin.[2]

Until recently, cancer was considered a lesser problem for Indigenous people because of competing factors affecting the population. Compared to other Australians, Indigenous people have: [2]
a shorter life expectancy than other Australians (estimated life expectancy gap of 9.4 years for females and 10.6 years for males)

- excess morbidity and mortality associated with other diseases or injuries.

There are significant differences in the cancer experience of Indigenous Australians compared with non-Indigenous Australians:[1, 3]

- cancer incidence and mortality rates are higher for Indigenous Australians
- cancer survival is lower for Indigenous Australians
- fewer cancer-related hospitalisations occur for Indigenous Australians
- there is a higher prevalence of cancer-related modifiable risk factors.

**The term 'peoples' is used to acknowledge the heterogeneity of the Australian Indigenous population, which includes many different language groups and cultures.*

Objectives

On completion of this supporting resource, you should be able to:

1. Understand the constructs of Indigenous culture and the impact of significant historical events on contemporary Indigenous society.
2. Interpret key epidemiological trends for cancer in the Indigenous population.
3. Discuss strategies to reduce cancer risk in the Indigenous population.
4. Demonstrate the ability to apply principles of cultural safety in cancer control activities.
5. Collaborate with Indigenous health care providers to develop person-family centred cancer care.
6. Provide culturally appropriate information and supportive services for Indigenous people affected by cancer.
7. Build collaborative networks with members of local Indigenous communities and Indigenous health care providers.

Key concepts

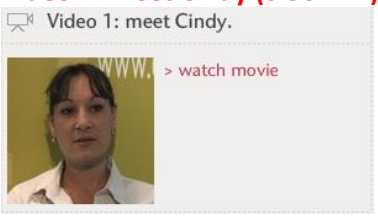
- Indigenous cultural constructs.
- Epidemiology of cancer.
- Cultural perspectives and cancer.
- Cultural respect principles.
- Cultural safety.
- Communication.

Video contributors

Five Indigenous health professionals from across Australia agreed to be filmed as part of this resource to share their knowledge and experiences.

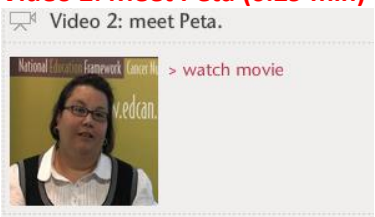
Introductory videos

Video 1: Meet Cindy (0.56 min)



Cindy Paardekooper is a Senior Aboriginal Health Educator at the Royal Darwin Hospital in the Northern Territory.

Video 2: Meet Peta (0.29 min)



Peta Jackson is the South Australian Aboriginal Project Manager for the Program of Experience in the Palliative Approach (PEPA) and is based in Adelaide.

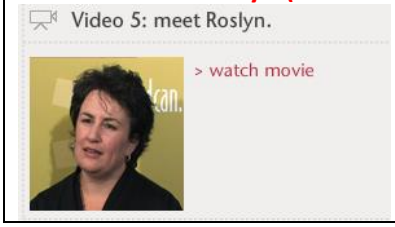
Video 3: Meet Cherie (2.24 min)

Cherie Waight is the Palliative Care Coordinator for the Victorian Aboriginal Community Controlled Health Organisation in Fitzroy, Victoria. (Note: this person passed away in 2014)

Video 4: Meet Catherine (0.27 min)

Catherine Jacka is a Project Officer at the Queensland Institute of Medical Research in Brisbane.

Video 5: Meet Roslyn (0.31 min)



Roslyn Lockhart is a Palliative Care Nurse based in rural New South Wales and a member of the Congress of Aboriginal and Torres Strait Islander Nurses.

Section 1: Epidemiology

Objectives

On completion of this section, you should be able to:

1. Identify cancer incidence, survival and mortality rates for the Indigenous population.
2. Describe factors contributing to trends in cancer incidence and mortality in the Indigenous population.
3. Identify the most common cancers types affecting Indigenous Australians.
4. Discuss cultural influences on perceptions of health and illness.
5. Access relevant Federal, State and Territory Government resources relating to Aboriginal and Torres Strait Islander health care.
6. Discuss strategies to reduce cancer risk among Indigenous peoples.

Cancer in Indigenous Australians

Reliable national data on the incidence and mortality of cancer for Aboriginal and Torres Strait Islander peoples are not available.[1, 3] A person's Indigenous status is not always recorded in cancer registry data.

Available data indicate inequities in health status and outcomes for Indigenous people generally, and in cancer outcomes in particular. Some evidence indicates that Indigenous people may experience a high burden of cancer morbidity and mortality, and poorer survival rates, compared to non-Indigenous Australians.[1, 3-6]

Between 2008 and 2012 in the Northern Territory, New South Wales, Victoria, Western Australia and Queensland: [81]

- An average of 1,189 Indigenous Australians were diagnosed with cancer each year, representing 1.1% of all cancer cases diagnosed in that period.[81]
- The age-standardised incidence rate for all cancers combined was significantly higher for Indigenous Australians (484 per 100,000) compared with non-Indigenous Australians (439 per 100,000). [81]
- The most commonly diagnosed cancers for Aboriginal and Torres Strait Islander peoples were cancers of the lung, breast in females, bowel, and prostate. [81]
- Indigenous Australians were 2.8 times as likely to be diagnosed with liver cancer, 2.2 times as likely to be diagnosed with cervical cancer, 2.0 times as likely to be diagnosed with lung cancer and 1.9 times as likely to be diagnosed with cancer of unknown primary site as their non-Indigenous counterparts. [81]

There is evidence of increasing cancer incidence in the Indigenous population, although the trend is slightly lower than in the non-Indigenous population.[3, 4, 7] The rise in cancer incidence rates in the Indigenous population can be partly attributed to improved access to screening services, particularly mammography and cervical cancer screening in rural and remote communities. [1] Participation rates are still significantly less than non-Indigenous Australians.[1] Implementation of culturally sensitive cancer awareness programs, which include involvement of Indigenous health workers, may have also increased people's awareness and participation in early detection programs.

Mortality data demonstrates significant inequities in the Indigenous experience. Between 2010 and 2014 in New South Wales, Queensland, Western Australia, South Australia and the Northern Territory: [81]

- There was an average of 512 cancer-related deaths for Indigenous Australians (1.6% of all deaths due to cancer).
- Indigenous Australians died from cancer at a younger age than non-Indigenous Australians.
- The age-standardised mortality rate for all cancers combined was higher for Indigenous Australians compared with non-Indigenous Australians (221 and 171 per 100,000, respectively)
- The most common causes of cancer death among Aboriginal and Torres Strait Islander peoples were cancers of the lung (670 deaths), liver (175), breast in females (155), and unknown primary site (175).
- Indigenous Australians were 3.8 times as likely to die from cervical cancer, 2.5 times as likely to die from liver cancer, and 1.8 times as likely to die from lung cancer as non-Indigenous Australians.

Survival statistics further demonstrate the inequities. Between 2008 and 2012 in New South Wales, Queensland, Western Australia and Northern Territory: [81]

- The five-year crude survival for Indigenous Australians was 43% for all cancers combined, which was significantly lower than for non-Indigenous Australians (57%).

- Compared with their non-Indigenous counterparts, the 5-year crude survival rate for Indigenous Australians was significantly lower:
    - for all age groups
    - for those living in all remoteness areas
    - for lung cancer (7% compared with 11%), breast cancer in females (70% compared with 81%), bowel cancer (47% compared with 53%), prostate cancer (63% compared with 72%) and cervical cancer (51% compared with 67%).

Learning activities	
Completed	Activities
☐	1 Access Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview[1], and: • Outline trends in overall cancer incidence, mortality and survival for Indigenous Australians. • Identify the most common cancers in male and female Indigenous Australians.
☐	2 Access the Executive Summary of the AIHW report Aboriginal and Torres Strait Islander Health Performance Framework 2008 report: detailed analysis[11], and identify factors that may increase the risk of cancer in Indigenous peoples in the following categories: • health status and health outcomes • health systems performance • determinants of health identity.
☐	3 Access The health and welfare of Australia's Aboriginal and Torres Strait Islander people: an overview 2011[12], and identify factors that may increase the risk of cancer in Indigenous peoples in the following categories: • socioeconomic • housing and transport • community capacity • behavioural • social and emotional wellbeing.

Supporting video

Video 6: Catherine (0.32 min)

Catherine discusses the impression Aboriginal & Torres Strait Islander people have of cancer.

Cultural constructs

An understanding of cultural constructs can help SCNs recognise differences and qualities that may be influenced by culture, and that need to be considered when planning person-centred care.

Misunderstanding or 'cultural blindness' that overlooks cultural differences can account for inequities in access to cancer control services. Examples:

- an SCN makes assumptions about the needs of an Indigenous person affected by cancer based solely on the SCN's experience and understanding of western culture
- an SCN provides information and education that does not reflect the cultural beliefs of different groups.

Culture can be conceptualised in many ways. The following definition is just one example:

Culture is 'a system of interrelated values active enough to influence and condition perception, judgment, communication, and behaviour in a given society'.[13]

Culture is a dynamic construct that changes over time, through generations of life experiences. For example, the term 'Values active enough to influence...'[14] has been used to emphasise how traditions may influence contemporary world views, but values and beliefs evolve and change from one generation to the next. Thus, a particular culture may honour traditional values of their predecessors but apply these in the context of the contemporary world.

Culture, health and health policy

Culture influences how people make meaning from life experiences and how they respond to situations. Culture therefore influences:

- how we view health and being healthy
- how we define illness
- how we respond to sickness.

Learning activities		
Completed	Activities	
☐	1	Discuss how you define health and being healthy.
☐	2	Discuss how your definitions may influence how you respond to being ill.

Health from the perspective of many Indigenous Australians means the well-being, integrity and harmony of self and all the community.[15]

Indigenous health policy documents define health:

'Health is not just the physical wellbeing of individuals but the social, emotional, cultural wellbeing of the whole community. This is a whole-of-life view and it also includes the cyclic concept of life-death-life'.[15]

The emphasis on community in this definition of health highlights the importance of *'inter-relationships between people and land, people and creator being, and between people'.*[15]

Learning activities		
Completed	Activities	
☐	1	Reflect on how Indigenous peoples' perception of health and being healthy is similar or different from your own.
☐	2	Take time to ask Indigenous people how they view health and what being healthy means to them.
☐	3	Consider the following statements: *'Over and over again... we heard of serious health problems being caused or exacerbated as a result of Aboriginal people and health professionals viewing common concerns in quite different ways.'*[16] *'What was seen as compassionate and humane treatment by the hospital staff was seen as something akin to being imprisoned by the patient and her family'.*[17] Reflect on the effects that differing views of health and illness can have on the way Indigenous people experience health care.
☐	4	Discuss implications for your practice as a cancer nurse if Indigenous peoples' perception of health and illness is different to more commonly held views in western society.
☐	5	'Closing the Gap' is a national campaign to reduce the inequalities between Indigenous and non-Indigenous life expectancy and general health status. Access key resources: • Closing the Gap in Indigenous Disadvantage. Council of Australian Governments.[18] • Closing the Gap. Oxfam Australia.[19] Identify the key elements of the Closing the Gap campaign and discuss how these elements may influence the development of cancer control programs in Australia.

Supporting video

Video 7: Catherine (1.13 min)

Catherine discusses the need to do a cultural assessment on yourself before dealing with an Aboriginal & Torres Strait Islander person.

Section 2: Constructs of cultural safety

Objectives

On completion of this section, you should be able to:

1. Explain the constructs of cultural safety.
2. Describe characteristics of Australian Indigenous cultures.
3. Understand the impact of significant events on modern Indigenous history.
4. Use a cultural appraisal framework to identify cultural factors relevant to cancer nursing.
5. Apply principles of cultural respect in providing care to Indigenous people affected by cancer.
6. Demonstrate effective communication processes when interacting with Indigenous people affected by cancer.

Cultural safety

'Public health programs [cancer control] should address what is and not what ought to be'.[20]

An important step in closing the gap in inequities in cancer outcomes for Indigenous people is to improve the cultural safety skills of service providers.

Cultural safety is a concept of care first advocated by the Maori nurses of New Zealand in the late 1980s. Cultural safety is concerned with power relationships between nurses and those in their care. The recipients of nursing care are empowered to decide what is culturally safe rather than complying passively with the authority of nurses or other health professionals.[21]

The underlying premise of cultural safety is based on a partnership relationship in which the vulnerable 'other' is at liberty to negotiate their nursing care even if that means nurses diverting from usual practice.[21] Too often the dominant health system aims to change behaviours and attitudes that are deeply ingrained in the cultural psyche of others.

Cultural safety requires a level of cognitive, attitudinal and personal skills that enhance communication and interaction with others.[22] Developing cultural safety is a process rather than an end point.[22] It involves personal reflective practice as a means of recognising values inherent in the culture of cancer nursing, and one's own culture, which may conflict with others.

Three steps towards cultural safety

Developing culturally safe practice requires the capacity to make adjustments to services that accommodate culturally different needs. The process of developing cultural safety involves individuals and organisations in three broad steps.[23]

Step 1: Cultural consciousness or awareness of the constructs of one's own culture and recognition of unique and similar qualities of other cultural groups. Engagement with minority cultural groups is imperative to the process of cultural consciousness and building collaborative cancer control programs.

Step 2: Cultural appraisal or assessment to identify cultural domains of difference that need to be considered in the plan of person-family centred cancer care.

Step 3: Cultural safety skill development of appropriate behaviours, attitudes, and communication strategies that reduce the gap of inequities in cancer outcomes.

Step 1: Cultural consciousness

At the heart of cancer inequities affecting Indigenous people is a 'cultural blindness' toward 'differences that make a difference'.[24]

This is not to say that cultural blindness is a deliberate act of avoidance by cancer service providers. It's more likely associated with a lack of knowledge about Indigenous people and their culture, and maybe even some apprehension about asking. The relative under-representation of Indigenous people in cancer services may present limited opportunities for service providers to engage with Indigenous people and learn about their different perspectives, values and beliefs in relation to health care.[7]

Learning activity	
Completed ☐	Activity 1 Name at least six famous Aboriginal and Torres Strait Islander people and explain why these people are well known.

A matter of identity

'Indigenous' is an English term ascribed by European imperialists to define the original inhabitants of a discovered country. Other European names assigned in various jurisdictions are first nation people, aboriginals or autochthons.

The process of naming others, according to Brazilian educator Paulo Freire, is 'a crafty instrument for the domination of one person by another'.[25] In other words, naming is an imposition of authority or control, an act of colonialism, which modern Indigenous societies are now contesting.

Australia's two Indigenous cultural groups, the Aboriginal people and Torres Strait Islander people, have similar and distinct cultural traditions, values and ways of life. Aboriginal people are of the land and their traditional ways of life herald from a hunter gatherer culture, while Torres Strait Islander people are associated with the culture of the sea.

Access the Australian Government culture portal[26] for more information about these two Indigenous cultures.

Supporting video

Video 8: Roslyn (1.41 min)

Ros discusses the fact that Aboriginal & Torres Strait Islander peoples are not always identified as such and/or not asked about their cultural background.

Heterogeneity

There is significant heterogeneity within Indigenous culture. This means that cultural mores, languages and social systems vary in different regions of Australia.

Before European colonisation there were hundreds of different tribes and at least 300 language groups, of which less than 20 or 30 remain.[24] The destruction of many Indigenous societies and languages are attributed to European colonisation in the 1870s, when policies controlled every aspect of people's lives. [25, 27]

Recently, tribal names, language groups and traditional lands have returned to the discourse on Indigenous identity as part of the decolonisation process in Australia. It's now accepted practice for

Aboriginal or Torres Strait Islander people to identify themselves by their tribal land and language group when addressing a public forum.

Examples of the ways in which Indigenous people may identify themselves include:

- an elder of the Gunbayngir people[28]
- belonging to the tribe Noonuccl from Minjeribah country[29]
- Gurindji woman or Yolngu man.[30]

Australian Aboriginal people in particular identify themselves by other names such as Yolngu (which is also written as Yolŋu), Nunga, Anangu, Koori and Murri, to distinguish between regional and tribal differences.[24, 31]

In Queensland and northern New South Wales (NSW), Aboriginal people use the term Murri or Goori to distinguish themselves from Kooris who are from other parts of NSW and Victoria, or Yolngu people from Arnhem Land in the Northern Territory. However, it's generally not appropriate for a non-Indigenous person to use these colloquial terms without permission when addressing Indigenous people.

It is a mark of respect for non-Indigenous people to acknowledge Indigenous Australians as the traditional owners and custodians of the land when addressing a public or professional gathering.

Examples of protocols for 'Welcome to Country' and 'Acknowledgement of Country' can be accessed from your local Indigenous community centre or health department.

Learning activity	
Completed	Activity
☐	1. Access and read your State/Local Government protocols for 'Acknowledgement of Country' and 'Welcome to Country'. Some examples: • Western Australia[28] • Queensland[32] • Victoria[30]

Supporting videos

Video 9: Cindy (0.22 min)

Cindy talks about the importance of culture

Video 10: Catherine (0.40 min)

Catherine talks about diversity amongst Aboriginal and Torres Strait Islander communities].

Video 11: Ros (1.45 min)

Ros advises of the need to be aware that Aboriginal and Torres Strait Islander peoples are not one homogenous group when considering communication; rather they are made up of many nations and people.

Cultural constructs

An important construct of Australian Indigenous culture is the historical journey since colonisation. Events of post-colonial history distinguish Indigenous Australian from other minority groups, and also imprint a legacy of tension in relationships with the non-Indigenous community. In the health care sector, these tensions can manifest as mistrust of providers and treatments and an inherent fear and ambivalence about the health care system.

From the perspective of colonised Indigenous people, the authority of western medicine was and for many still is regarded as part of the oppressive system of colonialism which denigrated their culture and traditions. Fanon explains: 'Introduced at the same time as racialism and humiliation, western medical science, being part of the oppressive system has always provoked in the native (sic) an ambivalent attitude'.[31]

Decolonisation

Decolonisation is a global movement underpinned by principles of cultural safety that decentre the focus of power or authority. The decolonisation movement advocates collaborations and partnerships that highlight the values and views of minority groups in shaping health care policy, planning, research, education and so forth.[21, 33, 34]

For nurses, critical to the process of decolonisation is reflection on personal assumptions and beliefs that influence the mode of practice and interaction with cultural minorities.[35]

Learning activities		
Completed	Activities	
☐	1	Access the NAIDOC website[36] and explain its role.
☐	2	Access the Australian Human Rights Commission website, 'bringing them home' section[37]. Discuss the key findings and recommendations of Bringing *them home: The 'Stolen Children' report* (1997).
☐	3	Access the Prime Minister of Australia's website[38]. Discuss the significance of the national apology delivered by Prime Minister Rudd on 13 February 2008.
☐	4	Access the Sorry Day and the Stolen Generations website[39] and discuss what the Day (26th May) commemorates.

Step 2: Cultural appraisal

The next step in the process of developing culturally safe practice is cultural appraisal or assessment. This is the process of identifying and valuing differences as cultural strengths rather than barriers which somehow have to be 'overcome'.

Cultural appraisal is a process of learning about domains or constructs of a culture that are pertinent to cancer control. It's also about recognising and respecting cultural strengths as an important focal point for developing appropriate interventions and cancer control strategies.

Identifying the cultural strength of any group cannot be done at a distance or by using a formula; it requires a relationship approach of learning from people and understanding the context of their world. Cultural strengths are the positive qualities, values, beliefs and traditions of a culture. In health care, these are likely to influence decision making about treatment and modes of care.[20]

Conceptual framework for identifying cultural strengths

Collins Airhihenbuwa[20, 24, 40] offers a complex framework called the PEN-3 model for analysing and appraising cultures. This conceptual framework comprises three subcomponents listed below from which the acronym PEN-3 is formed.

Domains of the PEN-3 model for appraising different cultures

Relationships and expectations
- Perceptions.
- Enablers.
- Nurturers.

Cultural identity
- Person.
- Extended family.
- Neighbourhood.

Cultural empowerment
- Positive.
- Existential.
- Negative.

The ICC framework

The Intercultural Cancer Council (ICC) in the USA has developed a practical tool for health care professionals involved in reducing the inequities of cancer outcomes for 'minority racial/ethnic patients and families'.[41]

The ICC framework is applied as a method of cultural appraisal, and is recommended for all cross-cultural encounters where the culture of the individuals requiring cancer care differs from those providing the care.

Components of the ICC Framework[41] for identifying and appraising cultural differences include:
- greeting and introductions
- communication mores and styles
- ethnicity - regional values/practices

- non-verbal communication styles
- relationships
- religion and spirituality
- belief/values associated with death and dying
- social distance and spacing.

Learning activities		
Completed		
☐	1	Describe how you define the cultural strengths of your cancer nursing practice.
☐	2	Discuss how you could learn about the cultural strength of a local Indigenous community.
☐	3	Access the resources below and describe examples of how the PEN-3 model has been applied in cancer control. • Recruiting African American men for cancer screening studies: Applying a culturally based model. Health Education and Behavior 32(4): 441- 451.[42] • Developing a culturally responsive breast cancer screening promotion with Native Hawaiian women in churches. Social Work in Health Care. 2008;33(3):169-77[43]
☐	4	Using the components of the ICC Framework,[41] describe an Indigenous culture in your region. Your engagement with the local Indigenous community, including Indigenous health care providers, is crucial for completing this learning activity.

Understanding the roles of stakeholders

In the interest of protecting the cultural integrity of the Indigenous population it is important for outsiders (non-Indigenous people) to follow protocols of cultural respect. Protocols for engaging with Indigenous organisations and communities can be accessed in many jurisdictions.

Establishing culturally appropriate cancer control requires the development of collaborative relationships with Indigenous health providers and their organisation.

Indigenous health workers

Indigenous health workers in a variety of health related occupations are an important part of the health workforce involved in cancer control activities. However, there is no uniformity across Australia in their roles, title, training, conditions of employment, and the ways they interact with other members of the workforce.

Access the Indigenous health workers webpage on the Australian Indigenous HealthInfoNet website[44] for more information.

The roles of Indigenous health workers can include:
- clinical functions (often as the first point of contact with the health workforce, particularly in remote parts of the country)
- liaison and cultural brokerage
- health promotion
- environmental health
- community care
- administration, management and control
- policy development and program planning.

Supporting videoa
Video 12: Cindy (0.34 min) Cindy discusses the role of the Indigenous health worker, & how one aspect of their job is to ensure the patient's cultural safety. **Video 13: Catherine (0.43 min)** Catherine talks about the benefits of the Indigenous health worker as someone who immediately understands Aboriginal & Torres Strait Islander culture. **Video 14: Catherine (0.34 min)** Catherine talks about how Indigenous health workers can support Aboriginal & Torres Strait Islander peoples in practical ways.

CATSIN

The Council of Aboriginal and Torres Strait Islander Nurses (CATSIN) was founded to formally represent Indigenous nurses. CATSIN recognises the unique contributions and commitment of Indigenous nurses in the area of health, and acknowledges the cultural expertise/knowledge that Indigenous nurses contribute to the health industry and nursing profession.

CATSIN's core business role is to increase the recruitment and retention of Aboriginal and Torres Strait Islander people into nursing. More information about CATSIN can be found by visiting their website.[45]

Learning activities	
Completed	Activities
☐	1 Access the Indigenous health workers webpage on the Australian Indigenous HealthInfoNet website[46], and: • Review the summary information about Indigenous health workers. • Identify Indigenous health workers in your local area.
☐	2 Access the cultural respect frameworks developed by your State/Territory government and/or other protocols for engaging with Indigenous organisations and communities such as Our lungs, our mob community education resource[80] [47], and list the key principles involved in engaging with Indigenous communities.

Step 3: Cultural safety, skill development and communication

Communication skills are highlighted as the third vital component of cultural safety. Without knowing the processes of communication according to others, health providers risk misinterpreting or overlooking the person's health related concerns. Inappropriate or ineffective communication can disadvantage minority groups in terms of access to cancer services available to other Australians.

The heterogeneity of Indigenous culture means that communication processes may not be the same for all Indigenous people. However, some key principles to consider in the process are described below.

Supporting video

Video 15: Roslyn (1.20 min)

Ros talks about the need for intuition and sensitivity, and advises getting to know your local Indigenous community.

Non-verbal communication

The use of silence and avoiding eye-engagement are features of communication for some Indigenous people.[17, 48] This can be misinterpreted as disinterest or indifference to the situation.[17, 34]

English is not always the primary language of rural and remote Indigenous people and even if they know a word or term it does not follow that it is understood.[17] Trudgen(2000) learnt from his considerable experience working in Arnhem Land that if the Yulngu people didn't understand the context or meaning of what a non-Indigenous person said, rather than ask questions or risk embarrassment, they responded by saying Yo yo (yes yes) to anything.[17]

Miscommunication is an important factor contributing to health inequities, as poor communication can block access to news and knowledge outside the domains of Indigenous people's culture:

'...what may be life-saving information from health professionals. It [poor communication] stops them [Indigenous people] knowing what they are giving consent for, how to comply with medical instructions and how to intervene in their own health problems'[17]

Use of silence

Silence and body language are important means of communication for many Indigenous people who regard this mode to be more telling than what is said.[17, 48]

Indigenous people often use silence when contemplating a question being asked and as a means of communicating with each other. Use active listening when in conversation with Indigenous people, allowing space for silence rather than trying to interject or pre-empt a reply.[17, 49]

Indigenous people may interpret non-Indigenous peoples' non-verbal communications (e.g. mode of dress, behaviour, body stance and facial expressions).

Indigenous people can feel daunted or intimidated by whiteman's authority as conveyed by persistent questioning, loud voices, being too close, rigid routines, and official uniforms.[50, 51] This apprehension toward authority is sometimes another remnant of colonisation, when white health authorities dominated Indigenous health matters and ridiculed traditional practices.[17]

A quieter tone of voice may be preferred to loudness, which can be considered aggressive and impolite.

Eye-engagement can be inappropriate when in conversation with some people, usually Elders. Speaking to a person indirectly using a quiet tone of voice is considered polite. This may not apply to all Indigenous people, so it's best to observe how people interact with others or ask your local Indigenous health worker or other health care providers.

Managing time

Different approaches to managing time and space can, if not respected, lead to misunderstanding and miscommunication between cultural groups.

Indigenous peoples' traditional perception of time as a cyclical process of events differs from the western cultural view of time as a linear, one directional segment or measured portion.[50, 52]

While traditionally-oriented communities may not adhere to western time measures, they still have a daily round of life and history marked by significant events. For example, the daily life in one community may be marked by the start of the school day, opening of the local shop, sunrise and sunset, full moon to new moon and so forth.[50]

This different perception of time may have implications for conventional routines and order which characterise western health care management and for methods of clinical assessment.

Supporting video
Video 16: Roslyn (1.12 min) Ros talks about taking the time to build rapport and a relationship, and how you may be viewed as culturally inappropriate if you do not take this time.

Developing relationships

A useful strategy for building effective, appropriate relationships with Indigenous people is to first give information about yourself before asking about and taking information from the Indigenous person and their family. Start with a conversation about everyday matters and share a bit of your personal self.

There are a number of resources available which provide information and guidelines for effective communication with Indigenous people. These include:

- Department of Health Reconciliation Action Plan[53]
- Queensland Government, Department of Aboriginal and Torres Strait Islander Partnerships[54]
- South Australian Government Aboriginal Cultural Respect Framework[55]

Learning activities		
Completed	Activities	
☐	1	Discuss what adjustments might be required in your work area to accommodate different perceptions of time if this was an issue for Indigenous people in your service.
☐	2	Discuss with your local Indigenous health workers or other members of the Indigenous community ways to effectively and appropriately communicate with Indigenous people in your region.

Section 3: Nursing care for Indigenous people with cancer

Objectives

On completion of this section, you should be able to:

1. Recognise factors influencing Indigenous peoples' perceptions of cancer.
2. Describe features of effective cancer prevention programs for Indigenous Australians.
3. Identify culturally appropriate resources and services for providing information and support for Indigenous people affected by cancer.
4. Explain nursing interventions to meet the health needs of Indigenous people affected by cancer.

Indigenous people's views of cancer

There is limited research about the meaning and psychosocial impact of cancer from the perspective of Indigenous peoples in Australia.

A qualitative study explored the meaning of cancer from the perspective of Aboriginal women in two rural communities in Queensland.[23, 34] Its key findings can help SCNs understand Indigenous women's attitudes toward cancer and their reluctance to undergo screening or follow-up treatment when a diagnosis of cancer is confirmed.

Supporting videos

Video 17: Cindy (1.50 min)

Cindy talks about how Aboriginal & Torres Strait Islander people view cancer, self-care & health priorities.

Video 18: Peta (0.46 min)

Peta talks about the need to explain processes & procedures in different ways to enhance understanding, & how this may need to be done visually or through an interpreter.

Attitudes towards cancer

The dominant attitude toward cancer is one of fear and fatalism. There is a general reluctance to talk about cancer as it's linked to a fear that just mentioning the 'C' word could prompt fate. Many Indigenous women assume that cancer is just one disease and fatal regardless of the site or stage of growth. Some believe cancer is contagious.

Avoiding the diagnosis by choosing not to follow-up abnormal test results

Aboriginal and Torres Strait Islander women who receive a cancer diagnosis chose one or two of several options:

- forgo treatment because they believe it to be futile
- negotiate to undergo treatment until the side effects become unacceptable
- prioritise family responsibilities over their own health needs
- deny the whole thing and 'get on with life'
- accept the diagnosis as just another problem in a difficult life
- seek traditional medicine and healing as the first line of treatment.

Cancer related treatments

Other reasons Aboriginal people may appear ambivalent about cancer treatment include:

- fear of being in a hospital linked to experience of racism and colonial mentality of staff
- the first point of decision making about treatment is the family
- fear of hospitals because of lingering spirits of people who have died
- lack of belief in the efficacy of treatment
- fear of being away from the community
- threat to cultural integrity imposed by hospital systems unsupportive of the individual's cultural needs
- fear of being 'cut up' by surgery which is viewed a violation of the 'sacred body'
- fear of surgery as it is thought to cause the spread of cancer

- no evidence of cancer survivorship in Indigenous communities.

Supporting videos

Video 19: Catherine (0.35 min)

Catherine talks about building knowledge & understanding in Aboriginal & Torres Strait Islander people affected by cancer.

Video 20: Peta (1.14 min)

Peta talks about being culturally sensitive to an Aboriginal & Torres Strait Islander person's needs, & how changes may need to be made to the hospital environment to enhance their stay.

Tradition

Many Indigenous people hold a belief in the authority of traditional medicine and healing practice. There is also a belief in the influence of 'bad spirits' that inflict serious diseases like cancer as a 'payback' for some cultural or relational misdemeanor.

Aboriginal people apportion blame for the disease of cancer on the whiteman's invasion of their land which colonised traditional lifestyles including diet, bush medicines and healing practices.

Supporting video

Video 21: Catherine (1.10 min)

Catherine talks about a cancer diagnosis being viewed by Aboriginal & Torres Strait Islander people as a 'death sentence'. She discusses how being sick is more than just physical, but also part of the spirit is damaged & needs to be healed.

Rural living

Barriers to cancer screening for women include concerns about confidentiality where life in contained rural communities is like living in a 'fishbowl'. When required to undergo screening services or treatments at health services in larger regional centres or cities, Aboriginal people may have to incur costs, travel considerable distances, and live away from their communities.

Cultural factors determine that family and friends need to be involved in the care of the sick person. Large numbers of people visiting can overstretch the facilities of the hospital ward or clinic. Aboriginal people from rural communities also like to have access to the outside environment, which may be prohibited by hospital infrastructure and geography.

Supporting video

Video 22: Peta (0.33 min)

Peta talks about liaising with the community the person is from & identifying it on a map to enhance cultural understanding & understand the remoteness of the location.

Decision making

Cultural mores about the privacy of women's and men's business mean topics relating to women's personal health are not discussed with men and vice versa. Family decision-making about treatment can sometimes manifest by women forgoing medical advice.

Gender and sexual implications

Women may feel 'shame' when expected to touch their bodies in ways recommended for self-examination. This sense of 'shame' also accounts for women's reluctance to undergo physical examinations and screening tests (such as Pap smear tests) in the presence of male health care providers. Faith and spiritual beliefs about the sacred body can sometimes prohibit violation by surgery.

Older women do not always consider themselves at risk of certain types of cancer, such as cervical cancer, if they are not sexually active. Many regard gynaecological cancers as 'dirty diseases' and assign the same social stigma as sexually transmitted diseases such as syphilis and gonorrhoea.

Supporting video

Video 23: Peta (0.25 min)

Peta talks about body language & awareness of cultural protocols with regards to hygiene & care differences for males and females.

Video 24: Roslyn (1.02 min)

Ros recommends SCNs talk to the local Aboriginal & Torres Strait Islander community. She advises using an Indigenous health worker as a resource/support person, who could be educated & upskilled to inform the patient/family in a culturally appropriate way.

Video 25: Peta (0.39 min)

Peta talks about advance planning, also called 'yarning', & how it is an individual's choice of place to pass away.

Cancer support and information services

There is a growing body of culturally appropriate information and support services for Indigenous people affected by cancer. Some good examples are:

- The Centre for Excellence in Indigenous Tobacco Control[56]
- Australian Indigenous Health InfoNet website[57] provides links to cancer information developed by various jurisdictions.

Contact your local Cancer Council or Indigenous health organisation to explore resources, information and support available for Indigenous people in your area. It may also be helpful to seek out resources from other jurisdictions. Examples include:

- For Aboriginal and Torres Strait Islander people. Cancer Australia. 2015[58]
- Cancer Council Victoria, Aboriginal Programs website[59]
- New South Wales Cervical Screening Program[60] (cervical screening materials for Aboriginal audiences).

Resource list

Other mediums to build your understanding of Indigenous culture

Examples of popular media sources include:

- Awaye![61] ABC Radio National, Monday 6pm, Saturday 3pm. Awaye! is produced and presented by Aboriginal broadcasters and is Australia's only national Indigenous arts and culture program. Awaye! covers music, arts, spirituality, politics, dance, literature, theatre. Awaye! is also a showcase for features and documentaries produced by Indigenous people overseas, including Maori, Polynesian, native American and South African broadcasters.
- ABC Online Indigenous[62] is designed to reflect current issues in the Indigenous community. It's a highly informative, dynamic and interactive space, showcasing creativity, developing online communities, encouraging social engagement in a rich media, multi-platform environment, offering audio and video downloads and user-upload opportunities.
- Speaking Out [63] covers culture, lifestyle and political issues affecting Aboriginal and Torres Strait Islander people in Australia. ABC Local Radio 9.30pm Sunday.
- Imparja[64] delivers information and communication services to the community, while promoting Indigenous culture and values. It has an ongoing commitment to its stakeholders and the development of its employees.
- NITV- National Indigenous Television- Foxtel[65]
- National Indigenous Radio Service[66]

Supporting stories

To increase the relevance of the following case studies to your work, it will help to:

- contextualise the given stories to an Indigenous community in your locality. Refer to the National Aboriginal Community Controlled Health Organisation[67] website to locate the Indigenous health council in your area.
- discuss the issues raised with your local Indigenous health worker or hospital liaison officer.

Story 1: Reducing cancer risk
Story 2: Early detection
Story 3: Bridging the gap
Story 4: Cultural safety
Story 5: Supporting choices (1)
Story 6: Supporting choices (2)
Story 7: Communicating needs
Story 8: End of life care

Story 1: Reducing cancer risk

Roy, a 19 year old Aboriginal man, understands the health risk of cigarette smoking, particularly since starting his university degree in primary health care. Roy still smokes and explains that it's very hard to quit because smoking is 'part of the culture' in his community.

Learning activities	
Completed	Activities The following resources may assist you to complete the learning activities. Tobacco: Time for Action[68] Smoking Cessation[69]
☐	1 Identify resources available to assist Indigenous people like Roy to quit smoking.
☐	2 Outline how you could assist Roy to develop a quit smoking program for his community.
☐	3 Discuss cultural considerations that may be required when implementing a health promotion program in an Indigenous community.
☐	4 Discuss the issues raised in this case with your local Aboriginal or Torres Strait Islander health worker or other health care providers.

Story 2: Early detection

Sue is a 34 year old single mother living in a rural Aboriginal community approximately three hours drive from the nearest cancer service. Sue presents at a women's health clinic in her community with symptoms of pain and vaginal bleeding on intercourse. Sue reports her last Pap smear test was after the birth of her daughter five years ago.

Learning activities	
Completed	Activities The following resources may assist you to complete the learning activities. Principles of Practice, Standards and Guidelines for Providers of Cervical Screening Services for Indigenous Women[70] Why Aboriginal women should have regular Pap smears[72]
☐	1 Identify factors that may influence Sue's reluctance to have regular Pap smear testing.
☐	2 Outline strategies you would employ to encourage Sue and other Indigenous women to participate in early detection and cancer screening programs.

Story 3: Bridging the gap

Aunty Emily is an Aboriginal elder living in a suburb within 10-15 kilometres from a city cancer hospital. Aunty Emily, who has not undergone Pap smear testing for 'years', reports that she has been having a few problems with vaginal bleeding and discharge, but felt too embarrassed to tell her husband and family.

Learning activities	
Completed	Activities
	The following resources may assist you to complete the learning activities. Overcoming Indigenous Disadvantage, Key Indicators 2014[73] Breast and cervical cancer in Indigenous women - overcoming barriers to early detection[74] A Cancer Journey for Remote Indigenous Patients in the Northern Territory[75]
☐	1 Discuss the factors that may have influenced why Aunty Emily has not presented for Pap smear testing in 'years'.
☐	2 Explain what strategies you would implement to ensure Aunty Emily's cultural safety when she is admitted to your cancer service.
☐	3 Identify resources your service has to inform and support Indigenous women affected by gynaecological cancers.

Story 4: Cultural safety

Norm is a 51 year old Indigenous man who lives in an island community in the Torres Strait. He presents at the local community health centre with symptoms of a persistent sore throat and productive cough with some blood specks which he attributes to the strain of coughing.

Norm is very reluctant to accept the advice that he needs to attend the regional health care facility on the mainland. Norm, who has smoked cigarettes since he was 14 years old, admits that his diagnosis is probably not too good.

Learning activities	
Completed	Activities
	The following resources may assist you to complete the learning activities. Sharing the True Stories, Evaluating strategies to improve communication between health staff and Aboriginal patients[76] A Cancer Journey for Remote Indigenous Patients in the Northern Territory[75] Clinical Practice Guidelines for the Treatment of Lung Cancer[77]
☐	1 Discuss the factors that may contribute to Norm's hesitancy about attending the regional hospital for further investigation.
☐	2 Explain what strategies you would employ to ensure Norm's cultural safety on his presentation at a regional health care facility.
☐	3 Identify supportive services and information you could offer to help Norm manage his condition should he maintain his stance to not attend a regional health care facility.

Story 5: Supporting choices (1)

Aunty May has been diagnosed with bowel cancer but, after consultation with her family, has refused surgical treatment, preferring to take her chances with more conservative methods.

Learning activities	
Completed	Activities The following resources may assist you to complete the learning activities. Australian Indigenous Health InfoNet website[57] Aboriginal and Torres Strait Islander Resources. Care Search - palliative care knowledge network[78]
☐	1 Discuss the factors that may influence Aunty May's decision about her treatment.
☐	2 Explain strategies you would use to ensure that Aunty May is fully informed about her treatment decisions.
☐	3 Identify supportive care services available for Aunty May once she returns home from an inpatient facility.

Story 6: Supporting choices (2)

Ben, who is 41 years old, is diagnosed with stage IV small cell lung cancer. Ben understands the connection between his smoking history which began in his early teens and states that 'smoking is part of the culture' in his community.

Ben travelled from his rural community to undergo some chemotherapy but later decided to forgo the treatment and return home to be with his family.

Learning activities	
Completed	Activities
	The following resources may assist you to complete the learning activities. Australian Indigenous Health InfoNet website[57] Aboriginal and Torres Strait Islander Resources. Care Search - palliative care knowledge network[78]
☐	1 Discuss the factors that may have contributed to Ben's decision to forgo treatment for his lung cancer.
☐	2 Identify supportive services that may help Ben when he returns to his rural community.

Story 7: Communicating needs

Uncle Jo, who is 54 years old, is hospitalised for symptom management of his advanced bowel cancer. He seems very uncommunicative and sad and, contrary to your expectation, has received very few visitors.

Learning activities	
Completed	Activities The following resources may assist you to complete the learning activities. Sharing the True Stories, Evaluating strategies to improve communication between health staff and Aboriginal patients[76] Aboriginal and Torres Strait Islander Resources. CareSearch - palliative care knowledge network[78]
☐	1 Discuss the communication strategies you would use to assess Uncle Jo's clinical and emotional needs.
☐	2 Identify the supportive care services for Indigenous persons admitted in your health care facility.

Story 8: End of life care

Pam, who is 39 years old, has undergone treatment for metastatic disease associated with a primary cervical cancer.

Pam expresses her appreciation of the cancer palliative care services but asserts her wish to return home to die in her community and to have better access to other healing medicines.

Pam's community has a primary health care facility with 15 inpatient beds which is a five-hour drive from the regional palliative care service.

Learning activities	
Completed	Activities The following resources may assist you to complete the learning activities. Clinical practice guidelines for the psychosocial care of adults with cancer[79] Aboriginal and Torres Strait Islander Resources. Care Search - palliative care knowledge network[78] A Cancer Journey for Remote Indigenous Patients in the Northern Territory[75]
☐	1 Identify and discuss some of the reasons that Pam may want to return to her community at this end-stage of her life.
☐	2 Explain how you would facilitate Pam and her family's access to appropriate palliative care services. List who you would contact regarding her discharge and for what purpose.
☐	3 Detail the discharge information you would supply to Pam and her family.

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