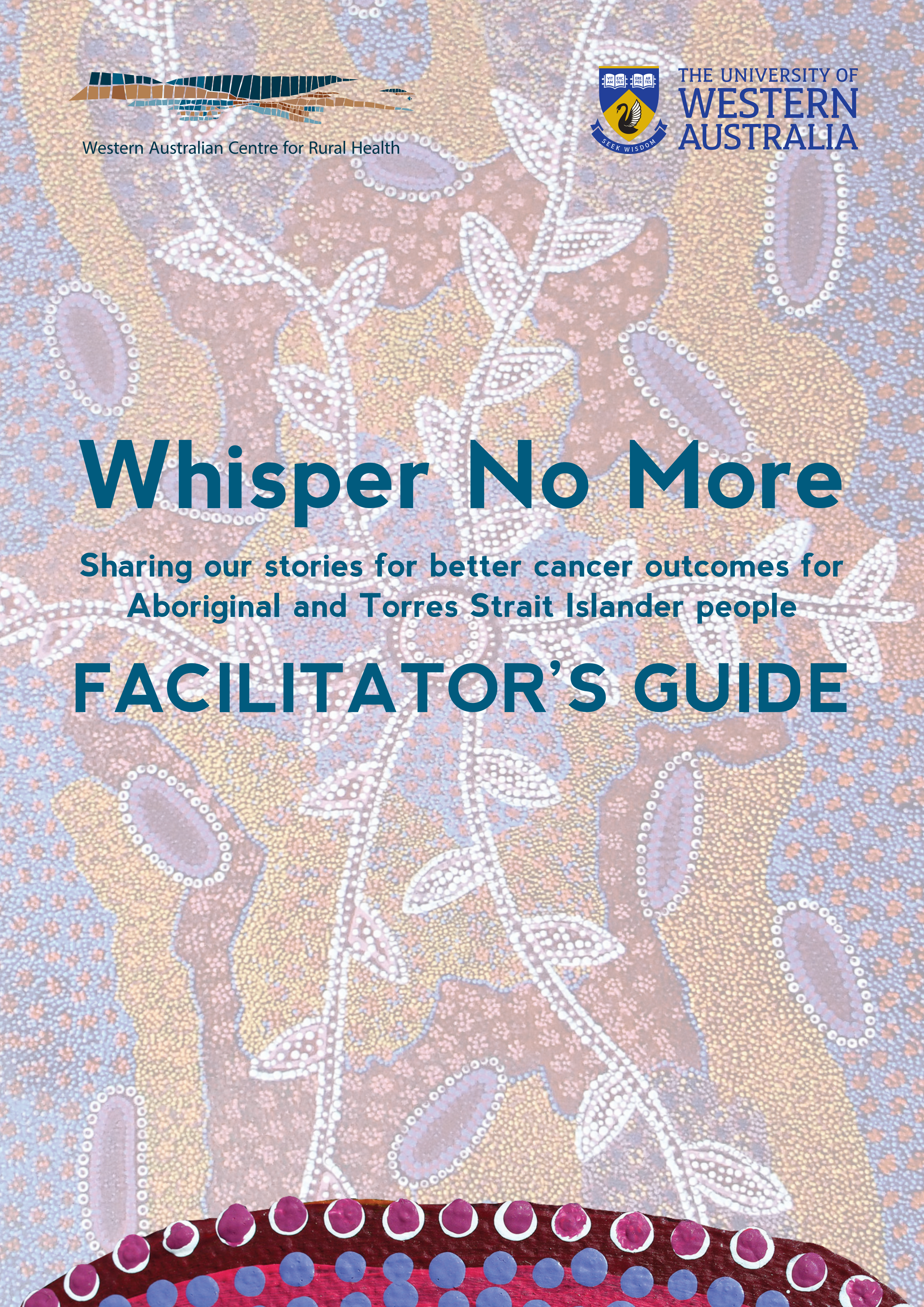

Western Australian Centre for Rural Health

THE UNIVERSITY OF
WESTERN
AUSTRALIA

Whisper No More

Sharing our stories for better cancer outcomes for Aboriginal and Torres Strait Islander people

FACILITATOR'S GUIDE

Whisper No More

was prepared and produced by:

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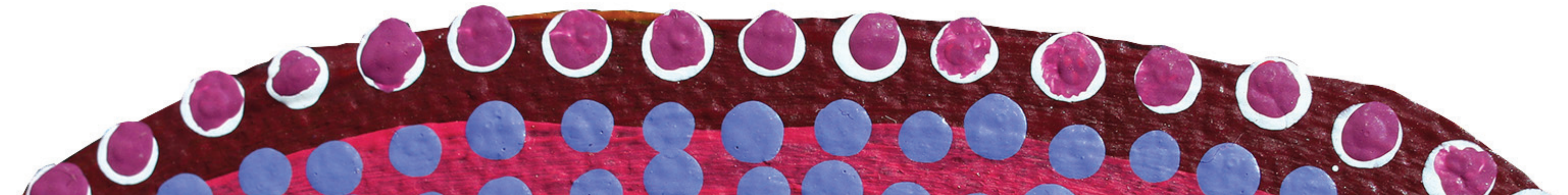

Table of Contents

Contact

We welcome your feedback on this resource, any comments you want to make or ideas you wish to share. Any difficulties with the WACRH website can also be reported.

http://www.wacrh.uwa.edu.au/

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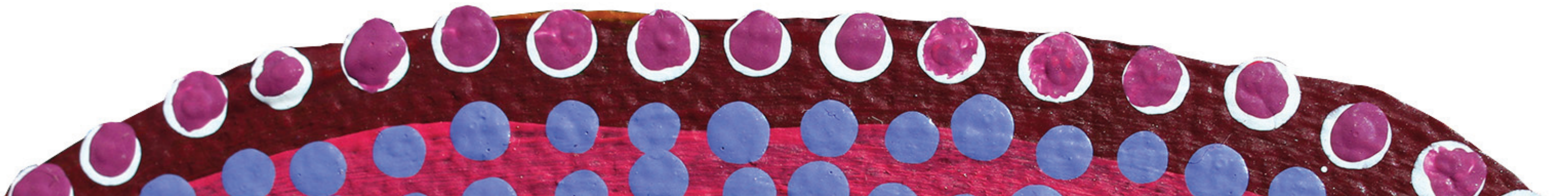
To access this resource online, go to the WACRH website (link above), click on the drop down menu on Aboriginal Health and select Whisper No More. This will take you directly to the login page. Alternatively, the direct link to the login page is: http://lms.wacrh.uwa.edu.au/login/index.php



Acknowledgements

Story Providers

Thank you to the Aboriginal people who shared their experience of cancer to help create this resource. Special thanks to Bella Cooper, Narelle Capewell, Deborah Woods, Jenny Brockman, Clarry Cameron, Mary Crowley, Kavita Pepper, James Poland and Annie Pepper.

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The Aboriginal and Torres Strait Islander Health Curriculum Framework was used to frame learning material for this resource. http://www.health.gov.au/internet/main/publishing.nsf/Content/aboriginal-torres-strait-islander-health-curriculum-framework

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Artwork

The painting featured in this resource is called Barndi Health. It was designed and drawn by Barbara Merritt and Charmaine Green (2015) who are Yamaji artists based in Geraldton, Western Australia. Charmaine is also a WACRH staff member.

Painting story: "In this painting we wanted to tell the story of how important it is to have good health and a healthy lifestyle. Like the blood veins and cells in our body connecting everything together. Eat good, live good, look after emotions and physical Barndi."

Introduction

Cancer is the second leading cause of death among Aboriginal and Torres Strait Islander (hereafter we respectfully use the term Aboriginal) people and there are many factors that contribute to their poorer outcomes from cancer: more advanced cancer at diagnosis, reduced access to/uptake of treatment, higher comorbidities, lower socio-economic status and language barriers. Cancer treatments normally occur in large urban treatment centres, and rural and remote Aboriginal patients suffer the additional disadvantage of geographic distance. Oncology teams may have trained and worked in urban settings and have little understanding of Aboriginal patients who they deal with.

In 2011 a community report, “A whispered sort of stuff”, summarised a body of research on Aboriginal people’s beliefs about cancer and their experiences of cancer care in Western Australia. The report and subsequent work on improving cancer outcomes for Aboriginal people identified a need for training of health science students and health care providers with information and support to help them understand the specific needs of Aboriginal people with cancer. Given that many Aboriginal cancer diagnoses occur late, there was a need to capture the voices of Aboriginal people and this provided the impetus to video record Aboriginal cancer patient’s stories about cancer. Their stories are now available on the WACRH website [http://www.wacrh.uwa.edu.au/] along with additional key information to encourage discussion and reflection to potentially change health care practice around working with Aboriginal patients with cancer, their families and community.

Aboriginal and Torres Strait Islander people are warned that some videos used in this package contain images and voices of people who are now deceased.

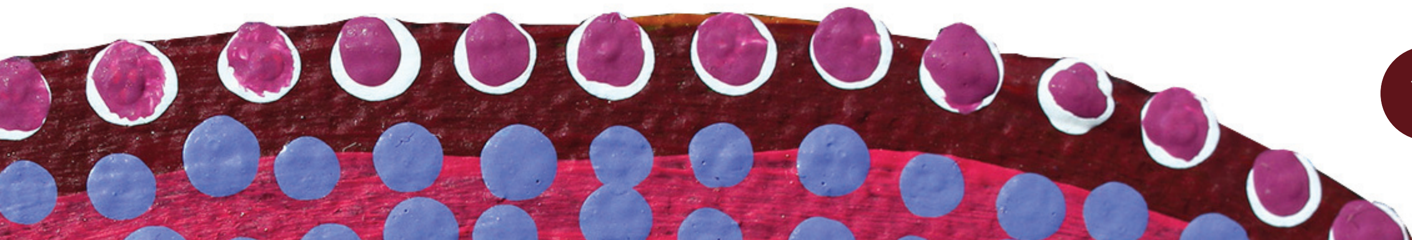
Learning outcomes

Aboriginal patients with cancer were asked to tell their story on video and agreed to use of the material to make resources for health professionals to help them develop their understanding of what matters to Aboriginal people when they have cancer. Topics covered in interviews include the person and their family, their symptoms and diagnosis, care seeking and delays in diagnosis, response to diagnosis, treatment, what helped them living with their cancer diagnosis, things they did to stay well and wishes for end-of-life care.

- Assist health science students and health care providers better understand how Aboriginal people experience cancer care and their beliefs about cancer.
- Use that knowledge to improve the way health care is provided for Aboriginal patients, their families and communities.

Recommended pre-reading

Thompson SC, Shahid S, Greville HS, Bessarab D. “A whispered sort of stuff” A community report on research around Aboriginal people’s beliefs about cancer and experiences of cancer care in Western Australia. Cancer Council of Western Australia, Perth 2011. Available from: https://www.cancerwa.asn.au/resources/2011-06-14-A-whispered-sort-of-stuff.pdf



Using this resource

This resource has five themed videos containing multiple interview extracts and eight video interviews with individual cancer patients.

The videos can be accessed at the WACRH website: http://www.wacrh.uwa.edu.au

Themed videos	Duration
"It took a long time" – delayed diagnosis	3.16
"Just get yourself checked" – screening	3.02
"As long as I've got family around" – family	2.14
"This girl's doin' alright" – staying strong	3.38
"You've got to prepare" – difficult conversations	5.42

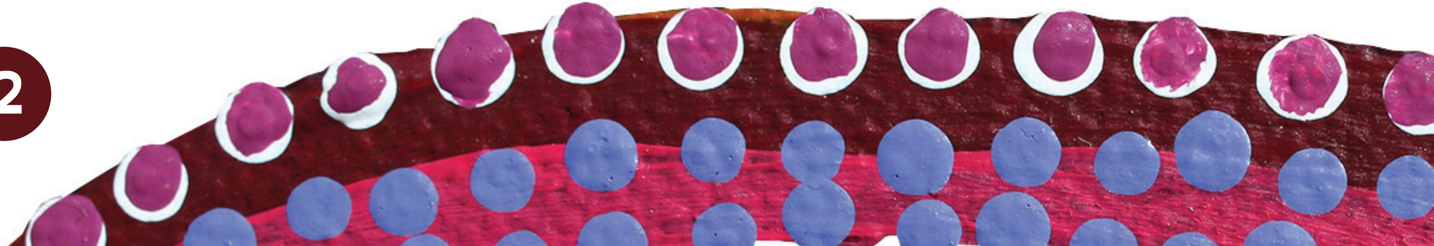
Individual stories	Type of cancer	Duration
Bella's story	Breast cancer	2.17
Deborah's story	Breast cancer	3.47
Clarry's story	Lung cancer	3.44
James' story	Lung cancer	3.11
Jenny's story	Throat cancer	2.08
Narelle's story	Bowel cancer	2.29
Mary's story	Bowel cancer	3.31
Kavita's story	Systemic mastocytosis	2.55

This resource has been set up to allow self-directed learning using the website or facilitated face-to-face sessions. Links to the resource or reference to specific themes can also be embedded into existing or new courses in cancer curriculum, palliative care or improving communication skills with Aboriginal cancer patients.

Teaching approaches

The way you use this package will depend on many factors – the number of learners you have, time and facilities available, the themes that are most relevant to learning outcomes, or the background and interests of those engaged in the session. If possible, involve Aboriginal and non-Aboriginal people in group discussion sessions as this will allow consideration of different perspectives.

If you want to embed one or more themes into an existing or new program, you may refer students to the WACRH website to do the relevant section/s by themselves. It would be great if you could give them the opportunity to discuss what they have learned in any face-to-face sessions. Ask questions about the themes or encourage them to share their understandings with each other or in small groups.



Teaching approaches continued…

Narratives lend themselves to face-to-face sessions and there are many ways to actively engage learners in large or small groups. We encourage you to be familiar with the resources available to find what best supports your learners and the intended learning outcomes. Below are some ideas, but don't be limited by them. Use what works for you and the people you are working with. The aim is to create a supportive, non-threatening learning environment. Be aware that discussions around 'difficult conversations' may bring out strong emotions and cancer stories from participants and people they know. We welcome any ideas you have or things that worked really well. Contact details are at the front of this package.

Think-pair-share

At the beginning of themed videos, viewers are asked to watch and listen, think about their reactions (this can be written in notes or allow a couple of minutes to just sit and think), then share their thoughts with others – either the person next to them or in a small group. This is a good way to get the conversation going. There are no right or wrong answers. The facilitator's role is to validate reactions, highlight what is similar and what is different in the group and use this as a lead in to the discussion of other questions.

Resource-based task

The themed videos contain discussion questions and key readings. Print off a theme sheet (without the feedback section) and readings. Divide into groups, allocate each group a theme sheet, readings and an individual story to view. Groups will need access to a computer, iPad or iPhone to view the videos and link to readings if printing is not an option. Each group discusses questions and reports back to the wider group. You can do this for a single theme or multiple themes.

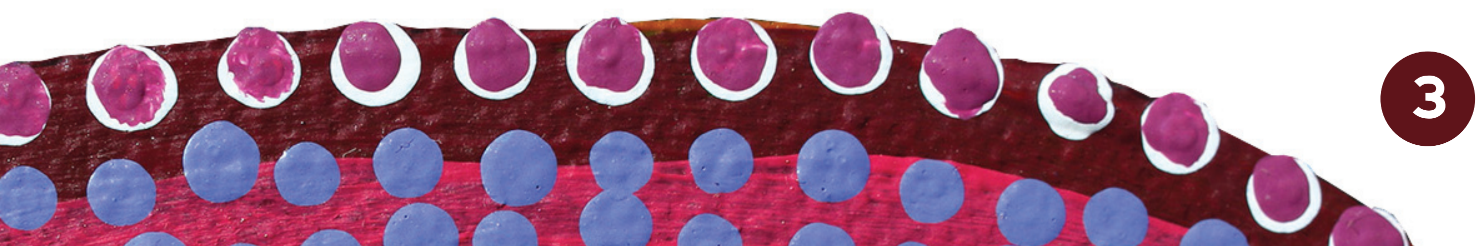
Example: For discussion questions 2 and 3 on the screening theme. Divide into small groups. Each group focuses on one person from the video – Narelle, Bella or Deborah. Groups view the theme 'screening' video again and also the individual story video. Also provide the key readings or access to the online readings and any other reading you consider relevant to the topic. Ask the groups to address questions 2 and 3 for their allocated person and present back to the whole group.

Jigsaw a theme

Produce a set of laminated cards with themes in this resource – delayed diagnosis, screening, family, staying strong and difficult conversations. On the back of each card, put the discussion questions on each theme or develop your own focus questions. Each group will be given one theme card, allocated one individual story video to view and access to key readings. The learners discuss or present the connection between the individual story and the theme. Alternatively, present a single theme and allocate the groups to different stories, then learners present the connection between their allocated story and the theme.

Flipped classroom

In this approach, learners working individually or in a group look at new material online before attending the face-to-face session. At this session, learners apply the concepts to different situations or contexts. So, for example, in the theme screening, learners could be directed to first engage with the online WACRH Whisper No More website. When they attend a face-to-face session, discussion could be on how to improve participation in screening in your local area. When looking at delayed diagnosis, discussion may focus on what the content in this theme means for changing practice in your context – what to be aware of and how to do it better. You might discuss ways to improve communication with Aboriginal people in your area or practise attentive listening in difficult conversations with a simulated patient.



Background infomation

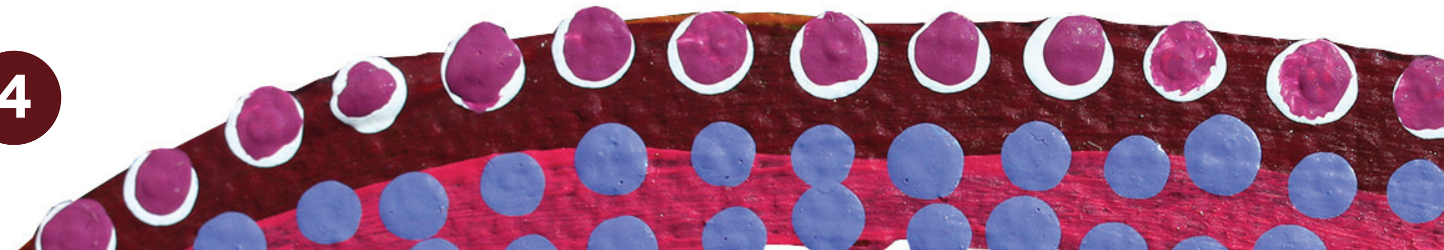
Aboriginal and Torres Strait Islander people are the first people of Australia. However, the developers of this resource are based in Western Australia which has a low number of Torres Strait Islander people and where the local people prefer to be referred to as Aboriginal (rather than Aboriginal and Torres Strait Islander or Indigenous). The participants in our research and the videos preferred the term Aboriginal. Therefore, in this resource we have used the term Aboriginal but respectfully acknowledge all Aboriginal and Torres Strait Islander people and the commonality of the issues that exists with respect to the themes explored. We trust no offence is caused or lack of inclusion of Torres Strait Islander people is inferred.

In the videos you will hear Aboriginal people talk about where they are from and places they call home. How Aboriginal people describe themselves is strongly linked to their connection with land and also influences kinship systems. It is important to be aware of this when working with Aboriginal people. There are many Aboriginal language and cultural groups in Western Australia. Some examples include:

Noongar – South West	Noongar country covers the whole South West portion of WA, including Perth. There are 14 different Noongar language groups.
Yamatji – Murchison and Gascoyne regions	This area includes towns like Geraldton and Meekatharra. The area is home to the Burringurrah community. This community is 480 kms east of Carnarvon, 390 km from Meekatharra and 70 kms from Mt Augustus – the world's biggest monolith which is twice the size of Uluru. The natural springs at the base of Mt Augustus have been a source of water for the local Wadjari people for thousands of years.
Wongai – Goldfields	The Wongatha people are the traditional inhabitants of the Wongai country of the Goldfields.
Kimberley peoples – Kimberley region	Today more than 30 Aboriginal groups remain in the Kimberley region. Almost half of the Kimberley population are Aboriginal with many people living in their traditional homelands.
Ngaanyatjarra – Central Desert region, also known as 'The Lands'	Ngaanyatjarra lands are vast, remote and covering over 250,000sq/km. About 2000 Aboriginal people live in 11 communities across The Lands.

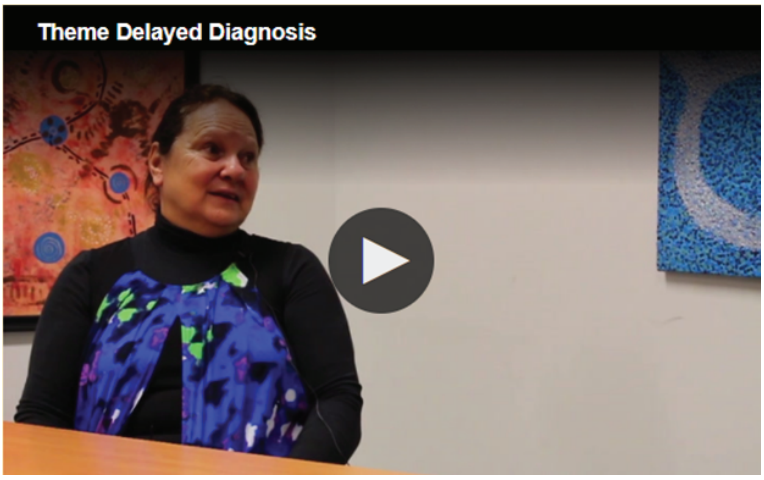
Other useful information links

- The AIATSIS map of Aboriginal and Torres Strait Islander people in Australia. https://aiatsis.gov.au/explore articles/aiatsis-map-indigenous-australia
- http://splash.abc.net.au/home#!/media/1916032/discover-the-diversity-of-australia-aboriginal-and-torres-strait-islander-languages
- www.CreativeSpirits.info, Aboriginal culture - History - Australian Aboriginal history timeline, retrieved 7 February 2018. https://www.creativespirits.info/aboriginalculture/history/australian-aboriginal-history-timeline



"It took a long time" – delayed diagnosis

Annie Pepper, who starts this video, is involved in cancer support after personal experience with cancer in her family. Annie makes the point strongly that delayed diagnosis for Aboriginal people is a very real problem. Stories from Jenny Brockman, Clarry Cameron, Narelle Capewell, Mary Crowley and Deborah Woods give you an insight as to why this is the case.



Links to individual stories

For more detail on this theme, you can link to the individual stories.

All the individual stories tell us something of the experience of delayed diagnosis, as well as covering other themes. But, these give particular insights for this theme.

- Jenny's story
- Narelle's story
- Clarry's story
- Mary's story
- Deborah's story

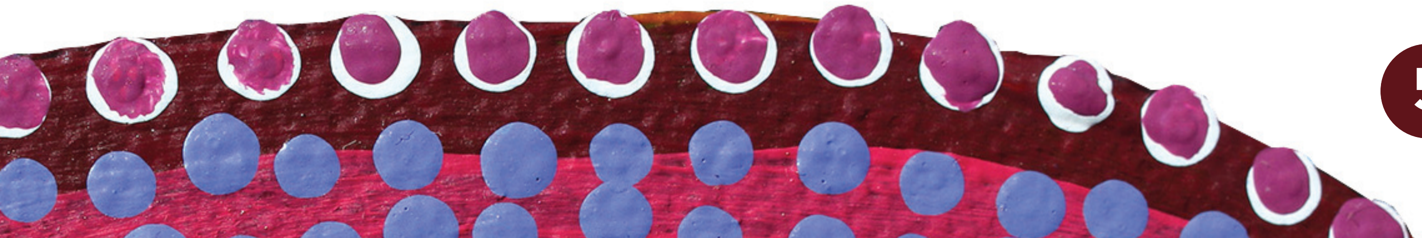
Discussion questions

1. As you listen to Jenny, Narelle, Mary, Clarry and Deborah talk about their experience, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues.
2. What factors contributed to delayed diagnosis for Jenny, Narelle, Mary, Clarry and Deborah?
3. In what ways could delays in diagnosis of cancer have been reduced for Jenny, Narelle, Mary, Clarry and Deborah?

Key readings

This first reading identifies factors contributing to delayed diagnosis of cancer for Aboriginal people (pages 3-7) and discusses areas to focus on for improvements (pages 7-9). The second explores beliefs and understandings about cancer that can also cause significant delays in seeking medical help.

- Shahid S, Teng T-W, Bessarab D, Aoun S, Baxi S. Thompson SC. Factors contributing to delayed diagnosis of cancer among Aboriginal people in Australia: a qualitative study. BMJ Open [Internet] 2016. Available from: http://bmjopen.bmj.com/content/6/6/e010909
- Shahid S, Finn L. Bessarab D, and Thompson SC. Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. BioMed Central [Internet] 2009. Available from: https://www.ncbi.nlm.nih.gov pmc/articles PMC2731745/



Feedback

Question 1

As you listen to Jenny, Narelle, Mary, Clarry and Deborah talk about their experience, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues.

There will be many different responses to this question. A teaching approach that may help get the conversation started and lead into discussion of the other questions may be 'Think-pair-share'.

Question 2

What factors contributed to delays in diagnosis for Jenny, Narelle, Mary, Clarry and Deborah?

It took nine months before Jenny was diagnosed with throat cancer even though she went to the hospital quite a few times. For Narelle, it took four years to be diagnosed with bowel cancer despite having many checks. Why? Multiple factors might be have caused delays in diagnosis here – beliefs around cancer being associated with pain, symptoms may have been under estimated, impacts of racism need to be considered, access to continuity of care where turnover of health professionals in rural areas is high and the costs of care may all have been factors contributing to delay.

Mary did not seek medical help for her back pain which eventually was diagnosed as advanced stage bowel cancer. Mary tells us she was too busy with work to get help and also, although her body was telling her to get help, her mind was telling her not to do anything about it. She may have presented with back pain but screening for bowel cancer was never triggered by health professionals. Fear of finding out what is wrong is common for many people but for Aboriginal people this may extend to fear of the whole health system, possibilities of leaving home to travel to urban areas, past experiences that have been traumatic, or doctors not initiating screening until patients are really sick.

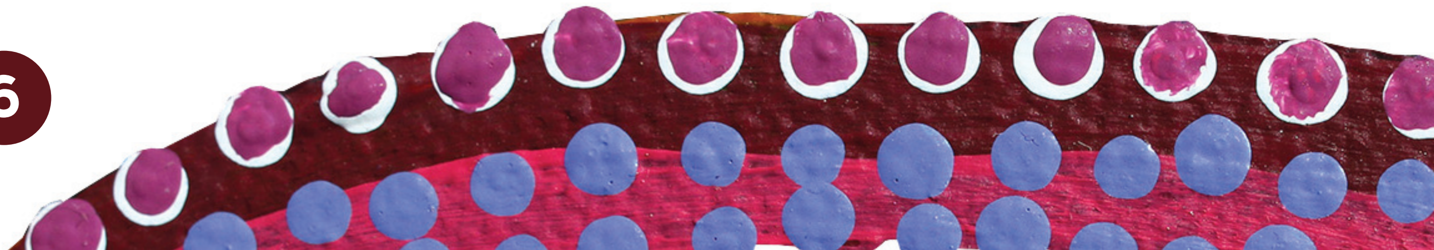
Clarry explains the "tough old bushman's way of doing things". Aboriginal men may be more reluctant to admit their symptoms and seek medical help unless it is something they perceive can be fixed, "like a broken leg", says Clarry. Beliefs about cancer can have a major impact on delays in diagnosis – read page 8 of "A whispered sort of stuff". Also have a look at the key readings by Shahid et al.

Like Mary, Deborah urges Aboriginal people not to be complacent and accept what the doctor is telling you – "go back and back until you are satisfied", she says. Miscommunication between patients and health care professionals can result in delays in diagnosis. Page 12 of "A whispered sort of stuff" looks at this in more detail. The article by Durey A et al (2012) on the reference list at the end of this document looks at the lack of cultural safety as a major reason for not accessing cancer services.

Question 3

In what ways could delays in diagnosis have been reduced for Jenny, Narelle, Mary, Clarry and Deborah?

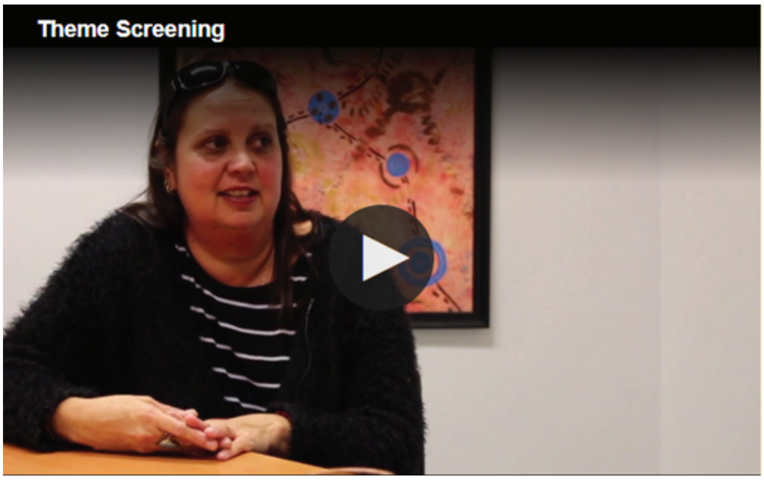
Refer to the first key reading by Shahid et al (2016), particularly pages 7-9. Discussion may focus on providing a culturally safe environment, investigating earlier and not being dismissive of symptoms, and improving communication. For communication, read the article on clinical yarning by Lin I et al (2016) on the reference list. Other factors that could improve cancer outcomes include, strengthening links between primary care physicians, specialists and cancer services, involving elders, Aboriginal health workers and communities to support health seeking behaviour and education, and the importance of sharing cancer stories with positive outcomes. Shahid et al (2016) also makes the point about being respectful in discussing the types and use of bush medicine. Discussion might lead to consideration of changes that could be made to existing health care practice in your context.



"Just get yourself checked" – screening

Aboriginal people do not participate in population-based screening for cancer as much as non-Aboriginal people, so cancers are often diagnosed later, at a more advanced stage. This topic explores why screening rates are lower and ways to improve screening participation, especially in relation to communication and support.

In this video Narelle Capewell, Bella Cooper and Deborah Woods share their experience with screening.



Links to individual stories

For more detail on this theme, you can link to the individual stories.

All the individual stories tell us something of the experience of screening, as well as covering other themes. But, these give particular insights for this theme.

- Narelle's story
- Bella's story
- Deborah's story

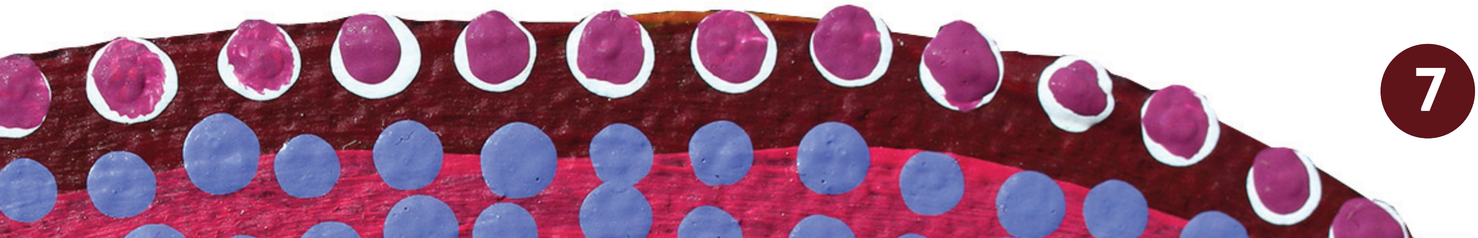
Discussion questions

1. As you listen to Narelle, Bella and Deborah talk about their experience, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues.
2. What factors contributed to delays in screening for Narelle, Bella and Deborah?
3. In what ways could screening have been improved for Narelle, Bella and Deborah?

Key readings

The first reading by Pilkington et al identifies barriers to screening (pages 6-7) and also enablers to screening (7-8). Findings from this study can be applied beyond breast screening to other population-based screening programs.

- Pilkington L, Haigh M, Durey A, Katzenellenbogen J, Thompson SC. Perspectives of Aboriginal women on participation in mammographic screening: a step towards improving services. BMC Public Health [Internet] 2017. Available from: https://bmcpublichealth.biomedcentral.com/articles/10.1186/ s12889-017-4701-1
- Lin I, Green C, Bessarab D. 'Yarn with me': applying clinical yarning to improve clinician patient communication in Aboriginal health care. Australian Journal of Primary Health. 2016;22(5):377-382 Available from http://www.publish.csiro.au/PY/pdf/PY16051



Feedback

Question 1

As you listen to Narelle, Bella and Deborah talk about their experience, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues.

There will be many different responses to this question. A teaching approach that may help get the conversation started and lead into discussion of the other questions may be 'Think-pair-share'.

Question 2

What factors contributed to delays in screening for Narelle, Bella and Deborah?

Narelle talks about being aware that bowel screening kits for over 50s were around but never really thinking about bowel cancer beyond that. She would not have known about possibilities of bowel cancer at an earlier age, symptoms and screening options. There is more to Narelle's story – take time to view her individual story.

Bella had her last breast screen in 2006. By the time she did another screen about 10 years later her breast cancer was well advanced. She attended a Woman's Health Day and it was a friend who encouraged her to do the screen. Bella mentions the van (a Breast Screen van is based in Geraldton but Bella lives in a small town 100km away) and lots of "sitting around" and "waiting that goes on and on". Lack of support, distance and the lengthy time involved may have made it difficult for Bella to attend regular screens.

Deborah's mum was diagnosed with breast cancer 12 months before she was. She explains that with this going on, being a busy mother and CEO, her focus was not on herself. Deborah also mentions the need to insist on a mammogram and not to be dismissed by "can't fit you in" or "can't do this, can't do that". Both these factors may have contributed to delays in screening for Deborah. Also consider that Deborah may not have known or was not advised of the need to get herself checked soon after her mother's diagnosis, given the family history.

Have a look at the key reading by Pilkington et al (page 6-7) for barriers to participation in screening.

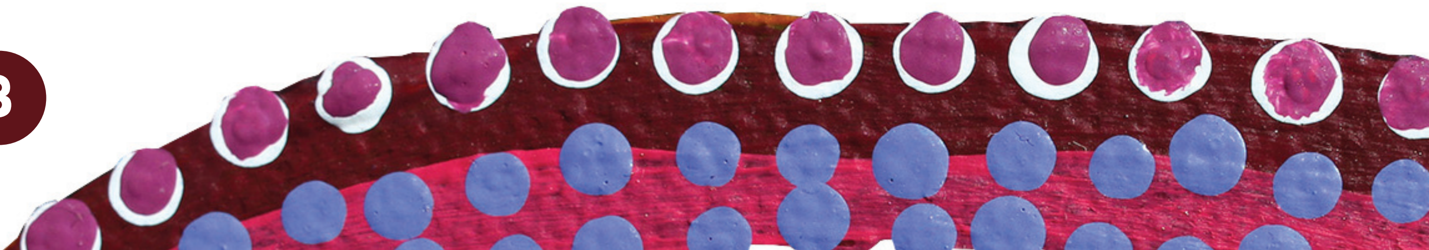
Question 3

In what ways could screening have been improved for Narelle, Bella and Deborah?

Communication and support are two fundamental aspects of facilitating screening for Aboriginal people. The reading by Lin I et al, talks about yarning and the move from the social yarn, to the diagnostic yarn to the management yarn. Think about Deborah's story. Her priorities as a daughter caring for her mother who has breast cancer, as a busy mother and CEO of the Geraldton Regional Aboriginal Medical Service meant she delayed screening. What could you have done as a health professional to encourage her to attend screening earlier? See Table 3 on page 10 of the Pilkington et al reading.

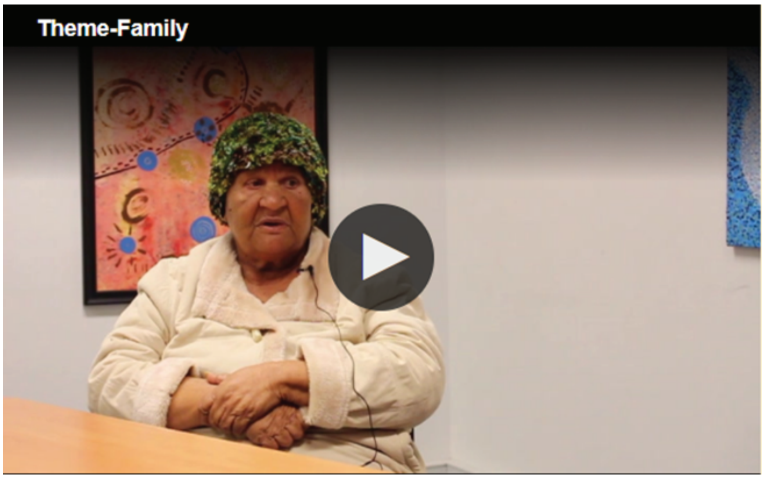
Refer to the key reading by Pilkington L et al (pages 7-10). Many 'enablers' are mentioned. Note the core elements of communication (having a yarn) and support in the Discussion section.

You may also like to discuss practical ways to implement strategies to improve screening in your local context or what it means for you as a health care professional working with Aboriginal patients.



"As long as I've got family around" – family

Family kinship structures and relationships have a big impact on how Aboriginal people cope with a cancer diagnosis. Decisions about treatment and care are often made with the family involved. As you listen to the stories from Bella Cooper, Kavita Pepper, Narelle Capewell and Deborah Woods, think about the role of family in their healing and well-being.



Links to individual stories

For more detail on this theme, you can link to the individual stories.

The central importance of family is a strong theme in all individual stories in this series. Link to any story for this theme. The ones below feature in this video:

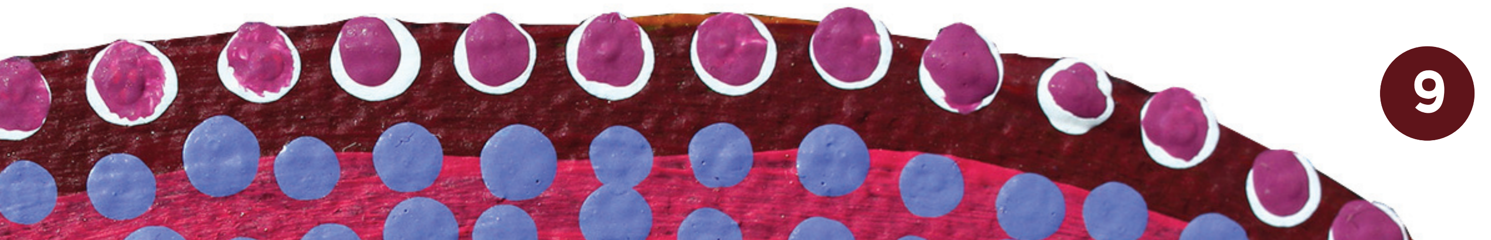
- Bella's story
- Kavita's story
- Narelle's story
- Deborah's story

Discussion questions

1. As you listen to Bella, Kavita, Narelle and Deborah talk about their family, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues.
2. What is the role of family in Bella, Kavita, Narelle and Deborah's cancer experience?
3. How can a health service accommodate the involvement of family in cancer care for Bella, Kavita, Narelle and Deborah?

Key readings

- Thompson SC, Shahid S, Greville HS, Bessarab D. "A whispered sort of stuff" A community report on research around Aboriginal people's beliefs about cancer and experiences of cancer care in Western Australia. Cancer Council of Western Australia, Perth 2011. See Section 4.2 and 5. Available from: https:/ www.cancerwa.asn.au/resources/2011-06-14-A-whispered-sort-of-stuff.pdf
- Durey A, Thompson SC, Wood M. Time to bring down the twin towers in poor Aboriginal hospital care: addressing institutional racism and misunderstandings in communication. Internal Medicine Journal. 2012 Jan; 42(1):17-22. Available from: http:/onlinelibrary.wiley.com/doi/10.111/j.14455994.2011.02628xabstract;jsessionid=75E814496FF17D875C316E88DA86E132.f04t03
- Thompson SC, Shahid S, Bessarab D, Durey A, Davidson PM. Not just bricks and mortar: planning hospital cancer services for Aboriginal people. BMC Research Notes. 2011 Mar;4(62). Available from: https://www.ncbi.nlm.nih.gov/pubmed/21401923



Feedback

Question 1

As you listen to Bella, Kavita, Narelle and Deborah talk about their family, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues.

There will be many different responses to this question. A teaching approach that may help get the conversation started and lead into discussion of the other questions may be ‘Think-pair-share’. You might notice the humour Bella and Deborah share in how they deal with things. You might also recognise the strength of the family bonds that exist for them all.

Question 2

What is the role of family in Bella, Kavita, Narelle and Deborah’s cancer experience?

Bella talks about her daughters and son-in-law shaving their hair on a day in Mullewa to show their respect, love and support (Mullewa is a town in the mid-west region of Western Australia, 450 kilometres north of Perth and 98 kilometres east-northeast of Geraldton). She says cancer is scary but “everyone is with you”. Kavita also talks about her family calming her down and blessing her. Narelle talks about her mum being with her through it all and Deborah says the special bond between mother and daughter has been strengthened. In addition to emotional support, Aboriginal families may provide social and financial support or assist in communication between patients and health professionals. ‘Aboriginal people place a high value on a holistic approach to health and well-being and this can affect their decisions around cancer screening, diagnosis and treatment’ (“A whispered sort of stuff”, page 12).

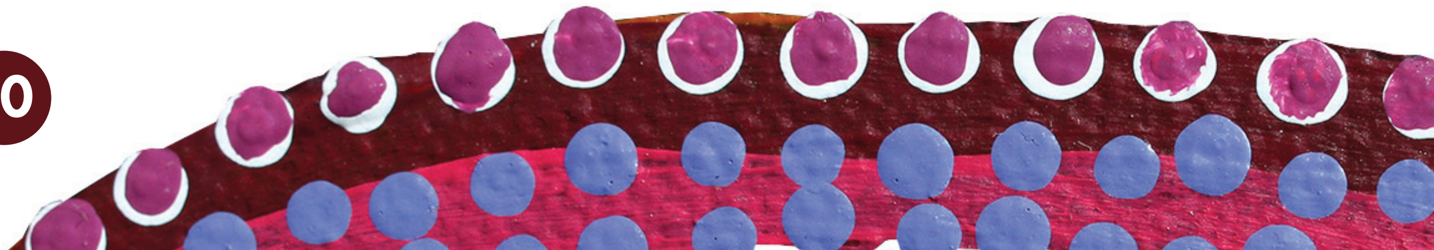
You might consider the support families also need throughout the cancer experience – access to information and support services or practical needs, so they can continue to support and advocate for their loved ones. Building relationships with family members will provide a strong indication of how the patient will respond to services and treatment. Health workers need be aware of family structures so they can communicate about medical status to the correct person (not always next of kin). Aboriginal liaison officers in the area might be able to help.

Question 3

How can the health service accommodate the involvement of family in a cancer patient’s care?

Having extended family around is important for Bella. She mentions her “grannies and great-grannies, running amuck around the hospital”. Section 4.2 of a “Whispered sort of stuff” outlines difficulties with the hospital environment when extended family visit. The reading by Durey et al also picks up on this point in terms of cultural safety and discusses the impact of institutional racism as a barrier to effective care. For some Aboriginal cancer patients, difficulties with the health system may also extend to transport, costs of medicines and treatments, and communication with doctors and other health professionals in dealing with cancer. Communication may be improved by not using jargon with the patient and family to make sure they all understand the meaning of what is happening. One strategy may be to ask the patient and family to ‘teach back’ the information given.

Discussion might then lead to what to do about involving family with examples of what works well in your local context. Also discuss possible changes in the health system and support services in your area. Section 5 “A whispered sort of stuff” and the Durey et al paper (see Mr K’s experience on page 21 and page 22 on possible ways forward) provide some recommendations to consider. Also have a look at the reading by Thompson SC et al as it talks about the people and social support being even more important than the physical environment.



"This girls doin' alright" – staying strong

"Cancer is a scary word, especially for Aboriginal people", says Annie Pepper, "but is it just a word and there are treatments". This is a key message for Aboriginal cancer patients to hear. In this video, Kavita Pepper, Bella Cooper, Mary Crowley, James Poland, Jenny Brockman, and Narelle Capewell talk about what helped them living with their cancer diagnosis and things they do to stay well.

Links to individual stories

For more detail on this theme, you can link to the individual stories.

The individual stories below feature in this video.

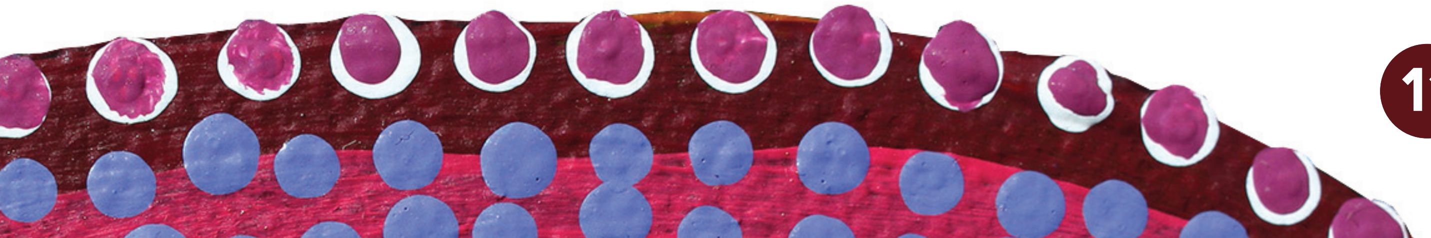
- Kavita's story
- Bella's story
- Mary's story
- James' story
- Jenny's story
- Narelle's story

Discussion questions

1. As you watch and listen to this video, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues.
2. What helps Kavita, Bella, Mary, James, Jenny and Narelle live and stay well with their cancer?
3. What beliefs do Aboriginal people have about cancer and how does this impact on cancer outcomes? How do stories, like the ones from Kavita, Bella, Mary, James, Jenny and Narelle, help change perceptions and attitudes?
4. What strategies can be used to support Aboriginal people to have a more positive experience to better manage their cancer?

Key readings

- Thompson SC, Shahid S, Greville HS, Bessarab D. "A whispered sort of stuff" A community report | on research around Aboriginal people's beliefs about cancer and experiences of cancer care in Western Australia. Cancer Council of Western Australia, Perth 2011. Available from: https://www.cancerwa.asn au/resources/2011-06-14-A-whispered-sort-of-stuff.pdf
- Shahid S, Finn L. Bessarab D, and Thompson SC. Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. BioMed Central [Internet] 2009. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC2731745/
- Green M, Cunningham J, O'Connell D, Garve G. Improving outcomes for Aboriginal and Torres Strait Islander people with cancer requires a systematic approach to understanding patients' experience of care Australian Health Review. 2017;41(2):231-233. Available from: http://www.publish.csiro.au/ahAH15214



Feedback

Question 1

As you watch and listen to this video, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues

There will be many different responses to this question. A teaching approach that may help get the conversation started and lead into discussion of the other questions may be 'Think-pair-share'.

Question 2

What helps Kavita, Bella, Mary, James, Jenny and Narelle live and stay well with their cancer?

Getting on with it and "continuing to do the things they do" as Annie explains, features in many of the stories. Humour plays an important part for Aboriginal people, especially when other people are around. "Don't let it get you down, just don't", says Bella. Mary maintains her interest in cooking, Kavita is strong minded and sports, music, fishing and her family keep her occupied. Jenny and James' fighting spirit comes through and Narelle takes more care of herself. Their stories show other Aboriginal people that treatments are available, it is scary, but that life goes on and positive things come from reassessing priorities in life and the support people get from family and others.

Question 3

What beliefs do Aboriginal people have about cancer and how does this impact on cancer outcomes? How do stories, like the ones from Kavita, Bella, Mary, James, Jenny and Narelle, help change perceptions and attitudes?

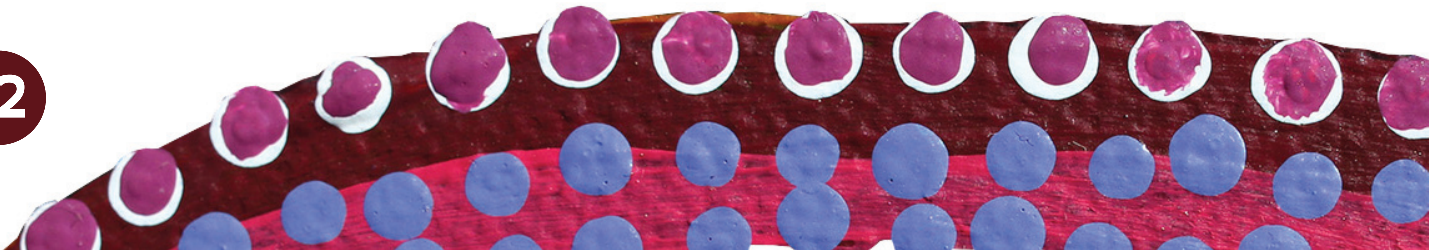
Aboriginal people experience a higher burden of cancer than other Australians, with higher mortality rates (for all cancers combined and for some specific cancers), a higher incidence of cancers with poorer prognosis, more advanced disease at diagnosis, higher rates of comorbid conditions and lower survival rates (Green et al, page 231). The underlying reasons for this is partially related to Aboriginal beliefs and experiences of cancer – misunderstanding, viewing cancer as a death sentence, fatalism, shame, preference for traditional healing, lack of cultural safety in the mainstream health service environment and miscommunication all influence the decisions Aboriginal people make around accessing health services and taking up cancer treatment ("A whispered sort of stuff", Section 4.1 and 4.2).

Improving outcomes for Aboriginal people with cancer requires an understanding of the patient's experience of care. Stories like the ones from Kavita, Bella, Mary, James, Jenny and Narelle, identify significant issues relating to their experience of cancer care. Their stories can help other Aboriginal people and potentially change the practice of health professionals. For example, primary health providers may consider earlier screening from Narelle's story, facilitating support from another Aboriginal woman worked for Bella, relevant information may have helped James link his cough with smoking at an earlier stage, and improving communication with patients like Jenny may have helped earlier diagnosis.

Question 4

What strategies can be used to support Aboriginal people to have a more positive experience to better manage their cancer?

Improved communication, provision of a culturally safe hospital environment, assistance with transport accommodation and care, involvement of local Aboriginal Medical Services, better coordination between health service providers all increase the willingness of Aboriginal people to access and participate in health care. Figure 2 on page 7 of the Shahid S et al reading summarises key lessons for health providers. Section 5 "A whispered sort of stuff" also outlines ways to support Aboriginal cancer patients.



"You've got to prepare" – difficult conversations

Death and dying is a sensitive topic for us all. It is important to understand that not all Aboriginal people share the same beliefs and customs but there are cultural expectations that families need to adhere to. For individuals, there are different wishes, approaches and reactions from family and friends. Listening is the most effective communication tool for all health care professionals. In this video Narelle Capewell, Mary Crowley, Jenny Brockman and Bella Cooper share their thoughts.

Links to individual stories

For more detail on this theme, you can link to the individual stories.

The individual stories below feature in this video.

- Narelle's story
- Mary's story
- Jenny's story
- Bella's story

Discussion questions

1. As you listen this video, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues.
2. Compare the stories from Narelle, Mary, Jenny and Bella. What differences and similarities do you notice about their wishes for end-of-life care?
3. What is the significance of country in the context of death and dying for Aboriginal people?
4. How can knowledge and access to quality end-of-life care services be improved for Aboriginal people with end stage cancer?

Key readings

- Shahid S, Bessarab D, van Schaik KD, Aoun S, Thompson SC. Improving palliative care outcomes for Aboriginal Australians: service providers' perspectives. BMC Palliative Care. 2013. 12(26). Available from: https://bmcpalliatcare.biomedcentral.comarticles/10.1186/1472-684X-12-26
- Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians: Palliative Care Australia. Available from: http://palliativecare.org.au.wp-content/uploads/2015/08/PCAPalliative-care-and-Indigenous-Australians-position-statement-updated-16-8-11.pdf
- Death and Dying in Aboriginal and Torres Strait Islander Culture (Sorry Business). http:/www.nslhd.healthnsw.gov.au/Services/Directory/Documents/Death%20and%20Dying%2in%20Aboriginal%20and%2Torres%20Strait%20Islander%20Culture_Sorry%20Business.pdf

Feedback

Question 1

As you listen to this video, what catches your attention? Reflect on your reactions, make some notes or share your thoughts with your colleagues.

There will be many different responses to this question. A teaching approach that may help get the conversation started and lead into discussion of the other questions may be 'Think-pair-share'.

Question 2

Compare the stories from Narelle, Mary, Jenny and Bella. What differences and similarities do you notice about their wishes for end of life care?

All are different in their priorities and focus. For Narelle, it is making her older children understand the seriousness of her stage of cancer despite seeing her 'well' and the close involvement of her mum in her wishes for her family. Mary is having a difficult time helping one of her daughters come to terms with her illness but is getting her affairs in order. For Jenny, burial not cremation is important and for Bella, her connection to country and that her family know and respect her wishes is important.

All have given some thought to end-of-life preferences. None talked about advance care planning or being aware of palliative care services. For both Bella and Jenny, connection with 'place' was important but they felt that they were not ready to think about it too much, "cross that bridge when come to it", says Jenny. Mary and Narelle found conversations with children difficult for different reasons. Gauging where Aboriginal people are at, their readiness to talk, and what is important to them is a starting point for health professionals. Attentive listening is vital in that conversation because everyone is different.

Question 3

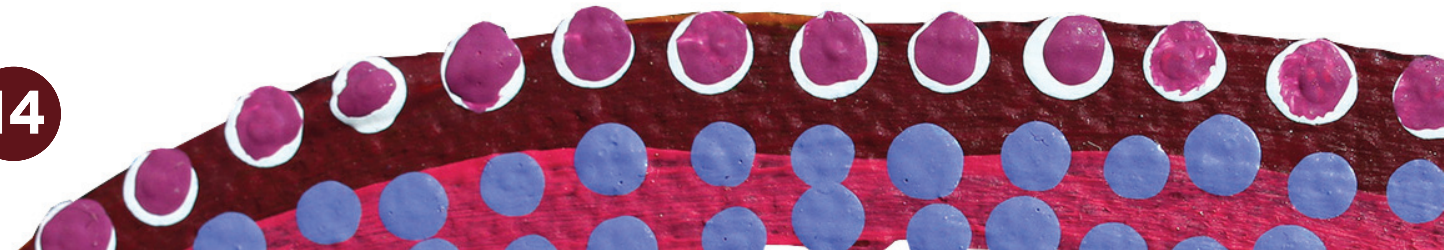
What is the significance of country in the context of death and dying for Aboriginal people?

'The opportunity for an Aboriginal person facing death to return to country (if possible) should be considered a high priority. It is important for them to pass away on the land on which they were born as the connection is profound and holds strong spiritual significance' (see page 17, Sorry Business) or the article by McGrath P on the reading list. How can this be facilitated, what are the challenges and what can you do if you can't send a person home? The reading by Shahid S et al will give you a perspective on this question.

Question 4

How can knowledge and access to quality end-of-life care services be improved for Aboriginal and Torres Strait Islander people with end stage cancer?

The reading by Shahid S et al identifies barriers and challenges to improving palliative care outcomes for Aboriginal Australians. Being aware of the broader socio-cultural context and how it affects willingness and ability to participate in palliative care services is the starting point to improving outcomes. In addition, an interprofessional approach is important and involving service providers to help accommodate large families and performance of cultural rituals and practices. Knowing who to contact for assistance with these issues be it Aboriginal liaison officers, health workers within the service or another service (contact via phone or video conferencing) to assist in facilitating family decision making. Also look at the reading from Palliative Care Australia (pages 3-5), particularly the section on culture, communication, geographical challenges, workforce, information/education, and local strategies as these are crucial factors for engagement and sustainable improvements in the quality of end-of-life care.



Individual stories

These stories provide the opportunity to know more about the people who contributed to this resource. A starting point for any health professional is to make connections and build trust with patients. For Aboriginal people, ‘yarning’ is a culturally appropriate way to exchange information and talk about what is important to them. The reference by Lin I et al, ‘Yarn with me’: applying clinical yarning to improve clinician-patient communication in Aboriginal health care, outlines a framework that has the potential to improve outcomes for patients.

The clinical yarn typically starts with a social yarn – knowing about connection to place or where an Aboriginal patient calls home, role in their community, kinship relationships and family support, cultural or sporting interests all allow understanding of the health issue in relation to the patient’s life story. Facilitators may ask learners to listen to these stories, and discuss how they shape their perceptions and the actions they may take. Think about involving Aboriginal and non-Aboriginal people in group discussions to explore different perspectives. Link back into the themed videos when appropriate.

Reminder…

The videos for individual stories can be found at the WACRH website. Click the drop down menu on Aboriginal Health and select Whisper No More. This will take you to the login page. Alternatively, you can go directly to the login page.

WACRH website: http://www.wacrh.uwa.edu.au

Login page: http://wacrh.uwa.edu.au/login/index.php

Bella's Story

Duration
[2 minutes 17 seconds]

Additional discussion questions

How does Bella describe herself – who she is, where she is from and what is important to her?

Family is important for Bella's health and well-being. Her family show their support and respect for her by visiting at the hospital. Bella mentions "grannies and great-grannies running amuck in the hospital". How can the hospital environment be made more welcoming for Bella and her family?

The physical environment is important but even more so is the person and social support received. The reading by Thompson SC et al Not just bricks and mortar, talks about the importance of holistic care for Aboriginal cancer patients.

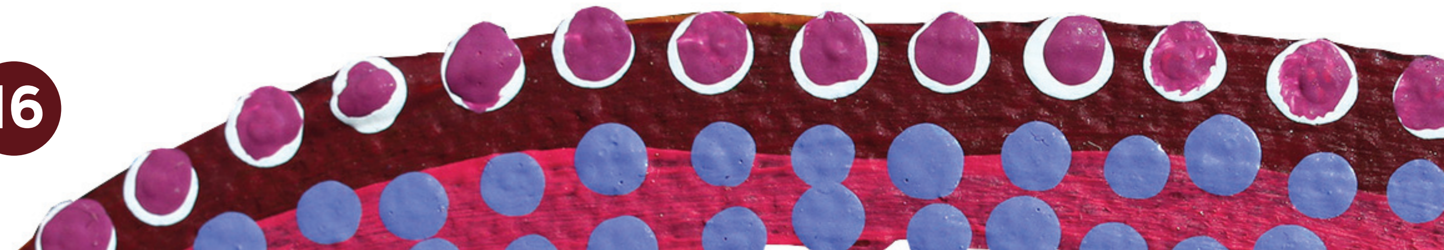
Key readings

- Thompson SC, Shahid S, Bessarab D, Durey A, Davidson PM. Not just bricks and mortar: planning hospital cancer services for Aboriginal people. BMC Research Notes. 2011 Mar;4(62). Available from: https://www.ncbi.nlm.nih.gov/pubmed/21401923
- [See page 15] Thompson SC, Shahid S, Greville HS, Bessarab D. "A whispered sort of stuff' A community report on research around Aboriginal people's beliefs about cancer and experiences of cancer care in Western Australia. Cancer Council of Western Australia, Perth 2011. Available from: https://www.cancerwa.asn.au/resources/2011-06-14-A-whispered-sort-of-stuff.pdf
- [Page 19] Durey A, Thompson SC, Wood M. Time to bring down the twin towers in poor Aboriginal hospital care: addressing institutional racism and misunderstanding in communication. Internal Medicine Journal. 2012 Jan; 42(1):17-22. Available from: http://onlinelibrary.wiley.com/doi/10.1111.1445-5994.2011.02628xabstract;jsessionid=75E814496FF17D875C316E88DA86E132.f04t03

Links to themed videos

Deborah's story can be linked to any of the themed videos, but the ones she features in are:

- Screening
- Family
- Staying Strong
- Difficult Conversations



Deborah's Story

Duration
[3 minutes 47 seconds]

Additional discussion questions

What do you find out about Deborah in her story?

Deborah is a busy woman with many competing priorities as a mother, daughter and CEO of the Geraldton Aboriginal Medical Service. How is it possible to encourage busy Aboriginal woman, like Deborah, to have a mammogram?

How might your own cultural background, values and beliefs impact on the relationship you develop with patients like Deborah?

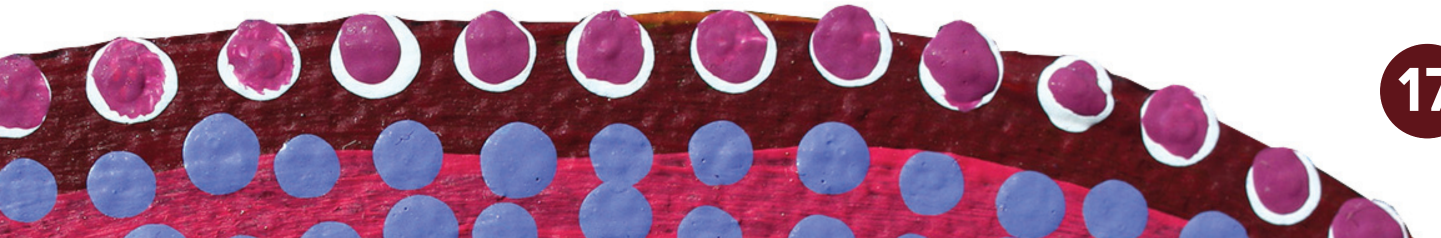
Key readings

- [Table 3, page 10] Pilkington L, Haigh M, Durey A, Katzenellenbogen J, Thompson SC. Perspectives of Aboriginal women on participation in mammographic screening: a step towards improving services. BMC Public Health [Internet] 2017. Available from: https://bmcpublichealth.biomedcentral.com.articles/10.1186/s12889-017-4701-1
- Durey A, Halkett G, Berg M, Lester L, Kickett M. Does one workshop on respecting cultural differences increase health professionals confidence to improve the care of Australian Aboriginal patients with cancer? An evaluation. BMC Health Service Research. 2017;17:660. Available from: https:/bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2599-z
- Queensland Health. Communicating effectively with Aboriginal and Torres Strait Islander people Available from: https://www.health.qld.gov.au/data/assets/pdffile/0021/151923communicating.pdf

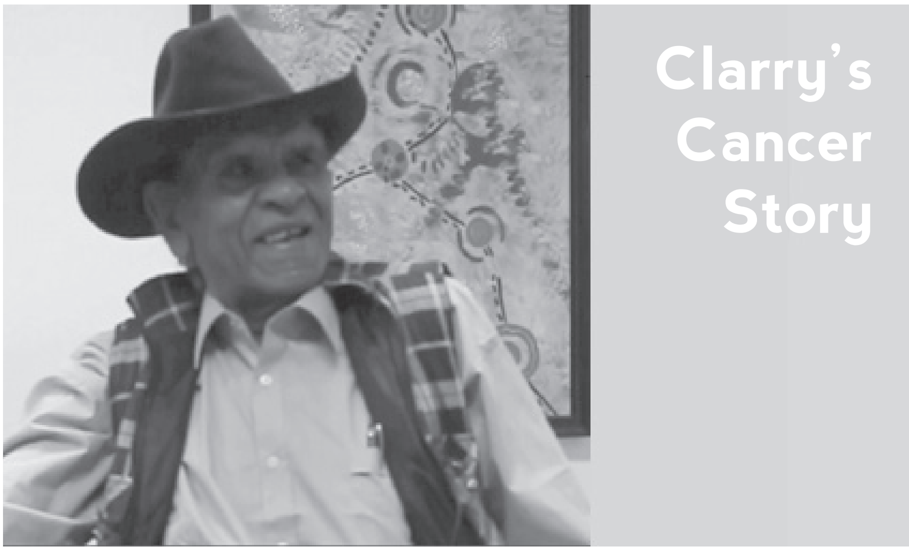
Links to themed videos

Deborah's story can be linked to any of the themed videos, but the ones she features in are:

- Screening
- Family



Clarry's Story



Duration
[3 minutes 44 seconds]

This link will take you to a map of WA. It will show you parts of WA the Clarry calls home. https://www.mapsofworld.com/australia/states/western-australia/

Additional discussion questions

Where does Clarry "call home"? Where is Mullewa?

How might Clarry's location impact on his access to cancer services and treatment?

Clarry mentions using maroon bush for his prostate cancer for 25 years before his lung cancer was diagnosed. Traditional bush medicines are commonly used by Aboriginal Australians. How would you discuss this in a respectful manner?

There are differences in views on bush medicines and cancer across Aboriginal and Torres Strait Islander groups and individuals. Why might health professionals need to know about these different views and use of traditional medicines in Aboriginal cancer patients?

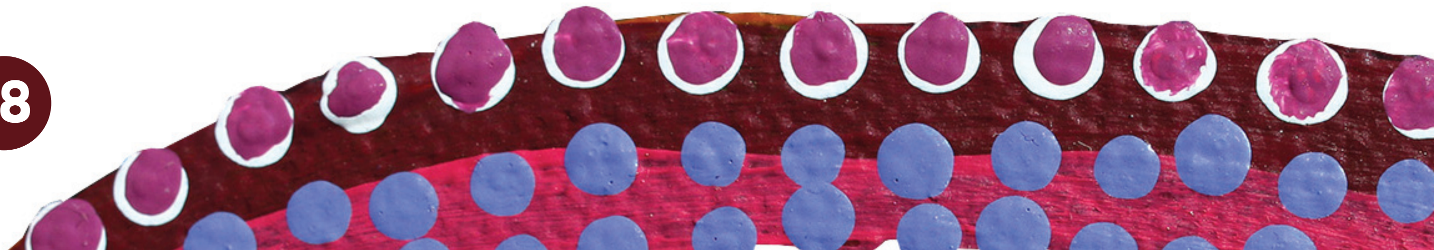
Key readings

- Shahid S, Bleam R, Bessarab D, Thompson SC. "If you don't believe it, it won't help you": use of bush medicine in treating cancer among Aboriginal people in Western Australia Journal of Ethnobiology and Ethnomedicine. 2010;6:18. Available from: https://www.ncbi.nlm.nih.gov/pmc/articlesPMC2902429/
- Van Schaik KD, Thompson SC. Indigenous beliefs about biomedical and bush medicine treatment efficacy for indigenous cancer patients: a review of literature. Internal Medicin Journal. 2011;Feb;42(2):184-91. Available from: https://www.ncbi.nlm.nih.gov/pubmed/21981135
- Maher P. A review of 'traditional' Aboriginal health beliefs. Australian Journal Rural Health. 1999;7:229 236. Available from: http://onlinelibrary.wiley.com/doi/10.1046/j.1440-1584.1999.00264.x/full

Links to themed videos

Clarry's story can be linked to any of the themed videos, but the one he features in is:

- Delayed diagnosis



James’ Story

Duration
[3 minutes 11 seconds]

This link will take you to a map of WA. It will show you where James comes from and how far he travelled for treatment. https://www.mapsofworld.com/australia/states/western-australia/

Additional discussion questions

What does James tell you about himself – who he is, where he is from and what is important to him?

What are some of the obstacles James would have had to overcome to get from Shark Bay /Denham to Perth for treatment on a regular basis (15 times, every two weeks)?

James was told the chemo was not doing any good. He has been sent home with tablets and oxygen to help his breathing. Family is a big thing for James and they are supporting him but he explains the hardest thing is thinking about “stopping a life” and “how much longer [he] has got”.

What things do you need to consider as a non-Aboriginal health professional to provide culturally safe end-of-life care?

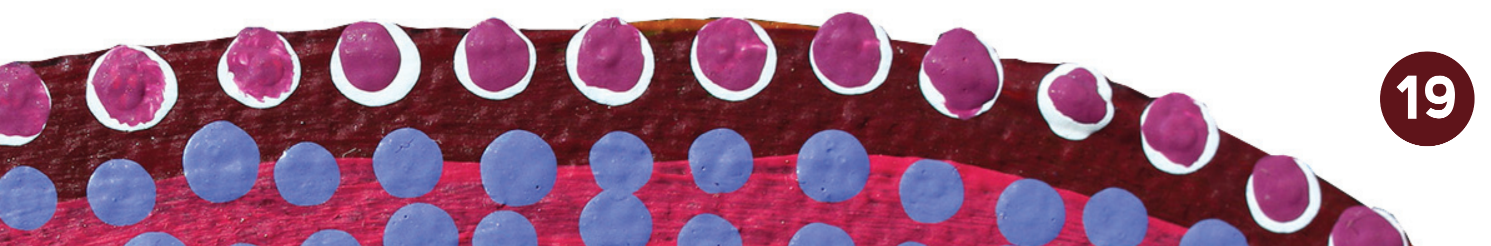
Key readings

- [Section 4.2, pages 9-17] Thompson SC, Shahid S, Greville HS, Bessarab D. “A whispered sort of stuff” A community report on research around Aboriginal people’s beliefs about cancer and experiences of cancer care in Western Australia. Cancer Council of Western Australia, Perth 2011. Available from: https://www.cancerwa.asn.au/resources/2011-06-14-A-whispered-sort-of-stuff.pdf
- Shahid S, Bessarab D, van Schaik KD, Aoun S, Thompson SC. Improving palliative care outcomes for Aboriginal Australians: service providers’ perspectives. BMC Palliative Care. 2013. 12(26). Available from: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/1472-684X-12-26
- Advance Care Planning Australia. A useful website with resources for health care professionals (see report on Respecting Patient Choices – Austin Health) with additional links for Aboriginal and Torres Strait Islander people. https://www.advancecareplanning.org.au/for-health-and-care-workers/invarious-settings/advance-care-planning-in-aboriginal-and-torres-strait-islander-populations
- Dying to Talk. Aboriginal and Torres Strait Islander Discussion Starter. http://dyingtotalk.org.au.aboriginal-torres-strait-islander-discussion-starter/

Links to themed videos

James’ story can be linked to any of the themed videos, but the one he features in is:

- Staying strong



Jenny's Story

Duration
[2 minutes 08 seconds]

Additional discussion questions

Where is Jenny from? What health services would be available to her there? Why did she go directly to the hospital and not a GP? What is important to her?

Jenny went to the hospital several times with chest pain. The focus of investigations was on her heart. It took nine months before throat cancer was finally diagnosed. What may have caused the delay in diagnosis for Jenny? Consider the article by Durey A and this issue of racism in Aboriginal health care.

An earlier diagnosis may have been possible with better communication with Jenny. What communication barriers may have existed for Jenny?

How can clinical yarning improve communication with Aboriginal people?

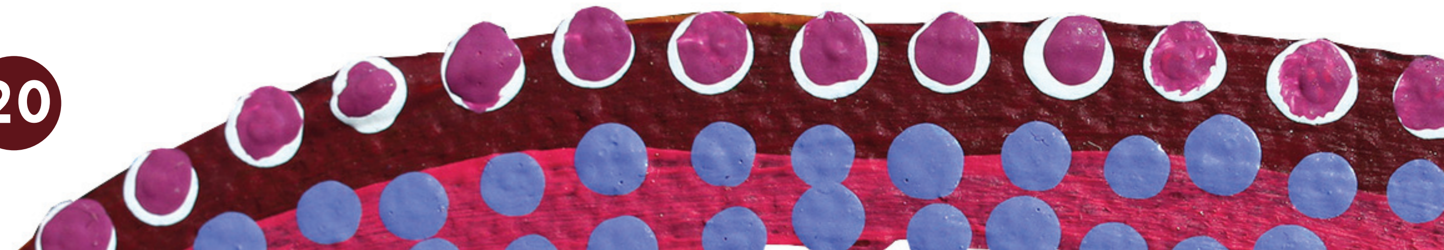
Key readings

- Lin I, Green C, Bessarab D. 'Yarn with me': applying clinical yarning to improve clinician patient communication in Aboriginal health care. Australian Journal of Primary Health. 2016;22(5):377-382. Available from http://www.publish.csiro.au/PY/pdf/PY16051
- Queensland Health. Communicating effectively with Aboriginal and Torres Strait Islander people. Available from:
  https://www.health.qld.gov.au/data/assets/pdf_file/0021/151923/communicating.pdf
- Durey A. Reducing racism in Aboriginal health care in Australia: where does cultural education fit in? Australia and New Zealand Journal of Public Health. 2010 July;34 Suppl 1:S87-92. Available from: https://www.ncbi.nlm.nih.gov/pubmed/20618302

Links to themed videos

Jenny's story can be linked to any of the themed videos, but the ones she features in are:

- Delayed diagnosis
- Staying strong
- Difficult conversations



Narelle's Story

Duration
[2 minutes 29 seconds]

Additional discussion questions

What do you notice about Narelle? Who is she and what is important to her?

Narelle mentions risk factors for cancer that should have triggered earlier screening. What were those risk factors and what does this mean for health professionals in terms of timing of screening for Aboriginal people?

What other factors might have contributed to the four year delay in screening for bowel cancer for Narelle?

Key readings

- [See page 5-6, diagnostic delay in GP clinics] Shahid S, Teng T-W, Bessarab D, Aoun S, Baxi S, Thompson SC. Factors contributing to delayed diagnosis of cancer among Aboriginal people in Australia: a qualitative study. BMJ Open [Internet] 2016. Available from: http:/bmjopen.bmj.com content/6/6/e010909
- Shahid S, Finn L. Bessarab D, and Thompson SC. Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. BioMed Central [Internet] 2009. Available from: https://www.ncbi.nlm.nih.gov/pmcarticlesPMC2731745/

Links to themed videos

Narelle's story can be linked to any of the themed videos, but the ones she features in are:

- Screening
- Family
- Staying strong
- Difficult conversations

Mary's Story

Duration
[3 minutes 31 seconds]

Additional discussion questions

What does Mary tell you about herself – who she is and what is important to her?

Mary had trained as a nurse and been working as the CEO of a network of Aboriginal Family Violence Centres before she retired. Even now, she continues to advocate and work for her community. Mary delayed going to see a doctor until she could not sit down or lie down and she knew she had a problem. She suffered from back pain but no screening was done.

What needs to change to trigger screening at an earlier stage for Aboriginal and Torres Strait Islander people?

What would encourage Aboriginal woman, like Mary, to participate in screening even if symptoms are not obvious initially or associated with something else (e.g. back pain)?

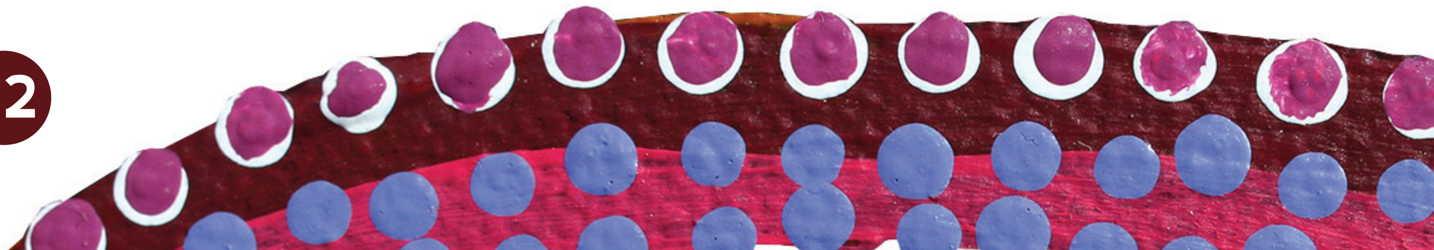
Key readings

- Shahid S, Teng T-W, Bessarab D, Aoun S, Baxi S, Thompson SC. Factors contributing to delayed diagnosis of cancer among Aboriginal people in Australia: a qualitative study. BMJ Open [Internet] 2016. Available from: http://bmjopen.bmj.com/content/6/6/e010909
- Shahid S, Finn L. Bessarab D, and Thompson SC. Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. BioMed Central [Internet] 2009. Available from: https://www.ncbi.nlm.nih.gov/pmcarticlesPMC2731745/

Links to themed videos

Mary's story can be linked to any of the themed videos, but the ones she features in are:

- Delayed diagnosis
- Staying strong
- Difficult conversations



Kavita's Story

Duration
[2 minutes 55 seconds]

Additional discussion questions

How does Kavita describe herself? Where is she from? What is important to her?

What is Kavita's illness, what would her symptoms have been? She mentions having to get a second opinion in the diagnosis phase and recommending this to other Aboriginal people if needed. "Don't back down", says Kavita. Getting a second opinion is also mentioned by Deborah and Mary in their stories.

In the first reading below the comment is made, 'Discrimination, racism and lack of cultural understanding mean that Aboriginal people still experience inequity and social injustice.'

What impact does this have on cancer outcomes for Aboriginal people? How can cancer outcomes be improved?

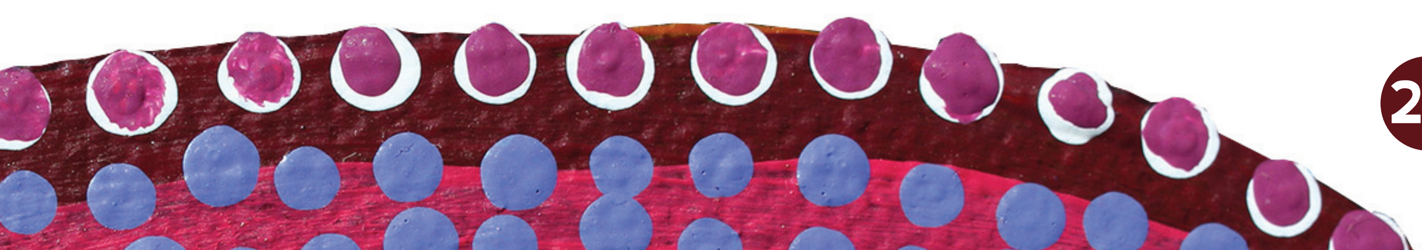
Key readings

- Queensland Health. Communicating effectively with Aboriginal and Torres Strait Islander people. Available from: https://www.health.qld.gov.au/__data/assets/pdf_file/0021/151923communicating.pdf
- Lin I, Green C, Bessarab D. 'Yarn with me': applying clinical yarning to improve clinician patient communication in Aboriginal health care. Australian Journal of Primary Health. 2016;22(5):377-382. Available from http://www.publish.csiro.au/PY/pdf/PY16051
- Durey A. Reducing racism in Aboriginal health care in Australia: where does cultural education fit in? Australia and New Zealand Journal of Public Health. 2010; July;34 Suppl 1:S87-92. Available from: https://www.ncbi.nlm.nih.gov/pubmed/20618302

Links to themed videos

Kavita's story can be linked to any of the themed videos, but the ones she features in are:

- Family
- Staying strong



Reference List

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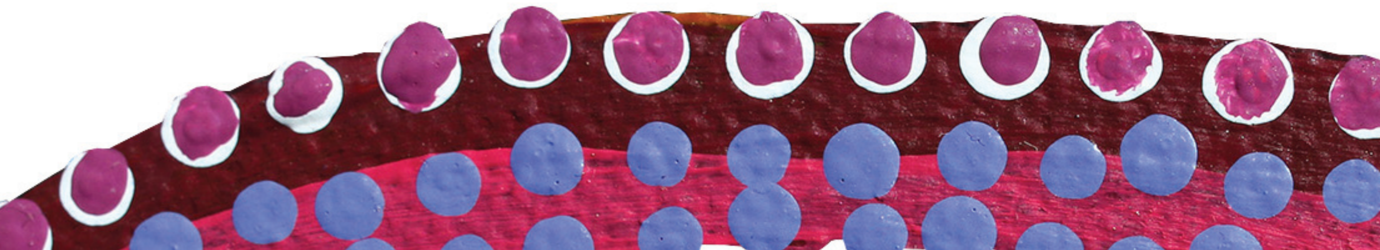

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Useful websites

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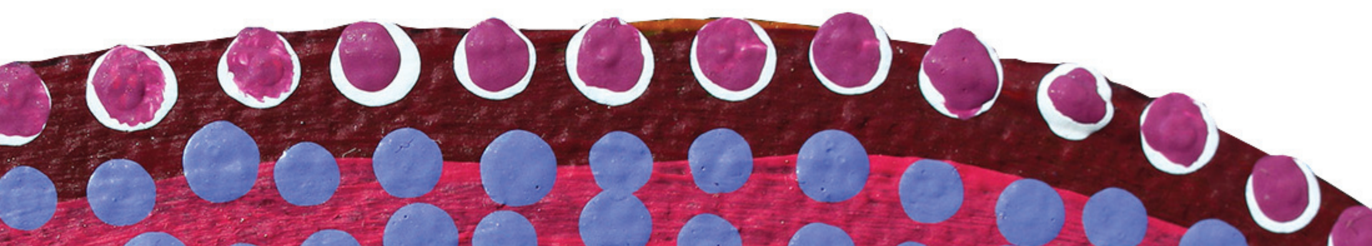
Cancer Council of Western Australia. Available from: https://www.cancerwa.asn.au/

Australian Indigenous HealthInfoNet. Available from: http://www.healthinfonet.ecu.edu.au/

Advance Care Planning Australia: A useful website with resources for health care professionals (see report on Respecting Patient Choices – Austin Health) with additional links for Aboriginal and Torres Strait Islander people. https://www.advancecareplanning.org.au/for-health-and-care-workers/in-various-settings/advance-care-planning-in-aboriginal-and-torres-strait-islander-populations

Dying to Talk. Aboriginal and Torres Strait Islander Discussion Starter.

http://dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter/



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