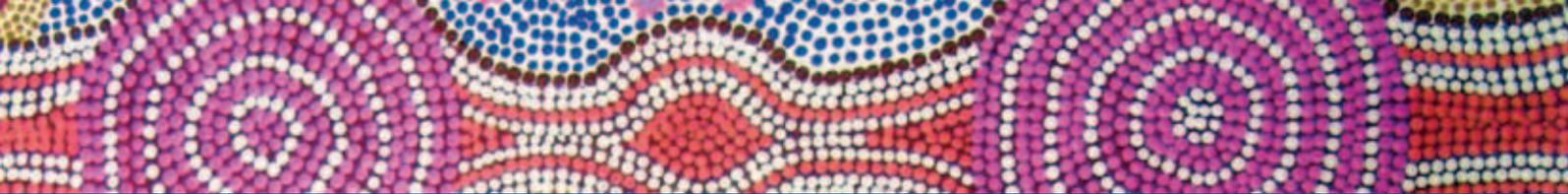


“A whispered sort of stuff”

A community report on research around Aboriginal people’s beliefs about cancer and experiences of cancer care in Western Australia

Sandra C Thompson, Shaouli Shahid, Heath S Greville, Dawn Bessarab





Artwork

The artwork featured in this report is from a painting called 'Relay for Life' painted by Geraldton-based Yamaji Art Centre artists Margaret Whitehurst, Charmaine Green and Barbara Merritt. The painting was donated to the 2009 Geraldton Cancer Council Relay for Life in recognition of all people who are affected by cancer, which knows no barrier. We thank Margaret, Charmaine and Barbara for allowing us to use their work in this report.

Acknowledgments

We thank all of the participants for sharing their stories and experiences and the many health service providers that assisted the process.

We acknowledge the invaluable contribution of the Aboriginal Reference Group and many other colleagues for their advice and assistance during this research, more than we name here. All of the following helped in various ways with this research: Leanne Pilkington, Francine Eades, Dot Henry, Gwen Rakabula, Michael Doyle, Peter Howat, Brian Bishop, Timothy Threlfall, Katie Thomas, Moyez Jiwa, John Mallard, Terry Slevin, Jude Comfort, Lizzie Finn, Kim Worthington, Anil Tandon, Ann Flynn, Joyce Trust, Rosemary McGuckin, Pam Haselby, Karina Powers, Annie Pepper, Pauline Gregory, Marisa Gilles, Rosemary Van den Berg, Kim Scott, Tracey Eades, Emma Croager, Sandra Eades, Sally Redman, Liz Brain, Gaby Bracks, Patricia Davidson, and Angela Durey - we thank them all.

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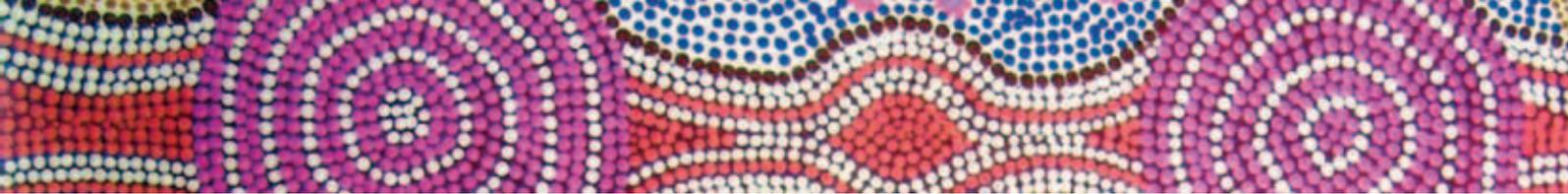
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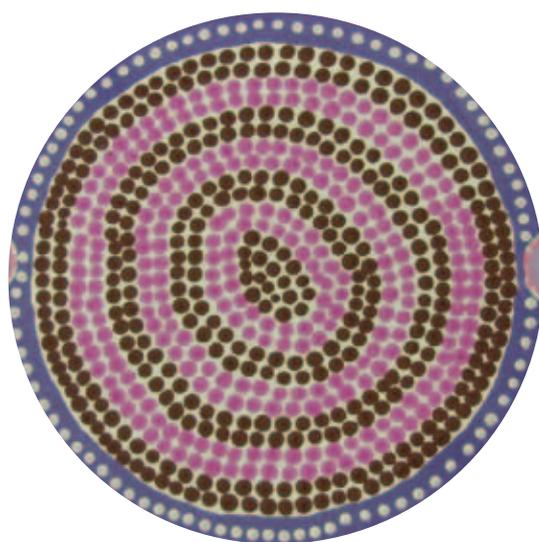
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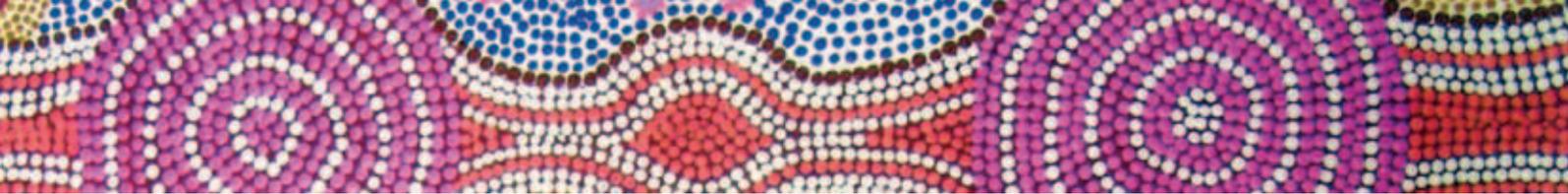


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Summary

This research project found out about Aboriginal people's experiences of cancer in Western Australia.

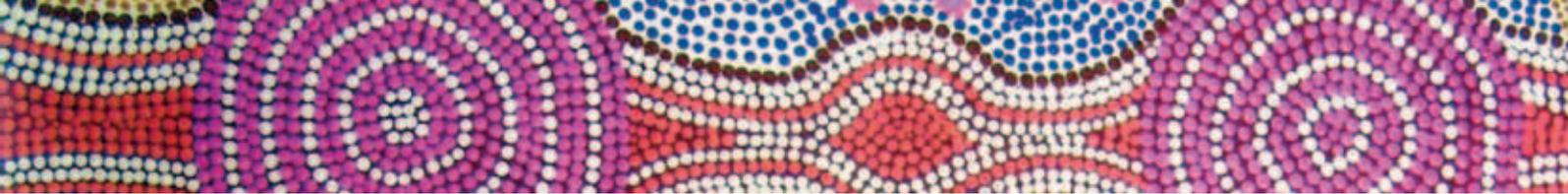
Cancer can be a serious problem but it can often be treated and people can go on to live a long life. Recognising symptoms of cancer and getting it treated early can make a huge difference.

From doing the research, we found that

- Aboriginal people are sometimes not aware of the symptoms of cancer and leave it too late to get things checked out.
- Sometimes Aboriginal people are afraid of cancer and don't want to get it checked out, or to talk about it. To break down this fear, we need to have more talking and sharing good stories in the community about Aboriginal people who receive treatment and survive cancer.
- Aboriginal people reported good and bad experiences of cancer services.

Things that can make cancer services better are:

- Helping people who need to go to Perth for treatment and explaining everything before they go so they know what to expect
- Getting more information to Aboriginal people about the Patient Assisted Travel Scheme (PATS)
- Having a liaison officer in the Hospital who makes sure the accommodation in Perth is right, and close to shops
- Making the hospital environment as friendly and welcoming as possible, including giving a welcome to Noongar country and welcoming extended family of patients
- Having food available in hospital that Aboriginal people like to eat, such as kangaroo
- Doctors need to take the time to make sure they explain things carefully and check that the patient and their family understand
- Good communication between local hospitals or clinics and the treatment hospitals in Perth will help Aboriginal people to have a good experience when they travel to Perth for treatment
- Aboriginal people need to have information about what kinds of support are available so they know what to ask for if they need help.



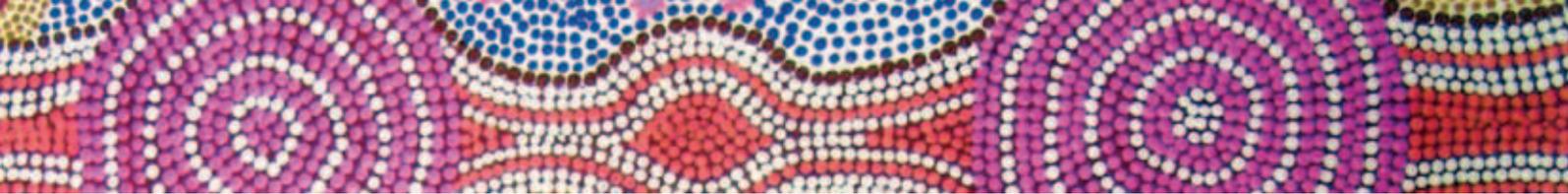
Recommendations

The research has made a number of recommendations to improve cancer outcomes for Aboriginal people.

The recommendations are listed at the end of this report:

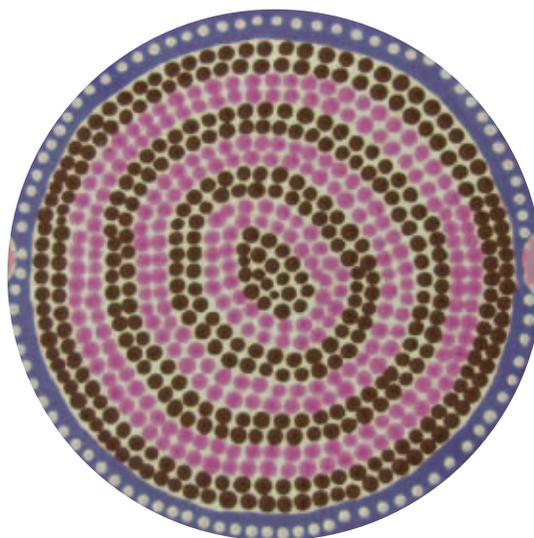
- Community education - getting more information in the community about preventing cancer and early diagnosis, and sharing more positive stories about treatment and recovery.
- Support systems such as transport, accommodation and hospital liaison services.
- The health system including transfer of care from the community to the hospital and back to the community, training doctors and other health staff to be more sensitive and responsive to Aboriginal needs.

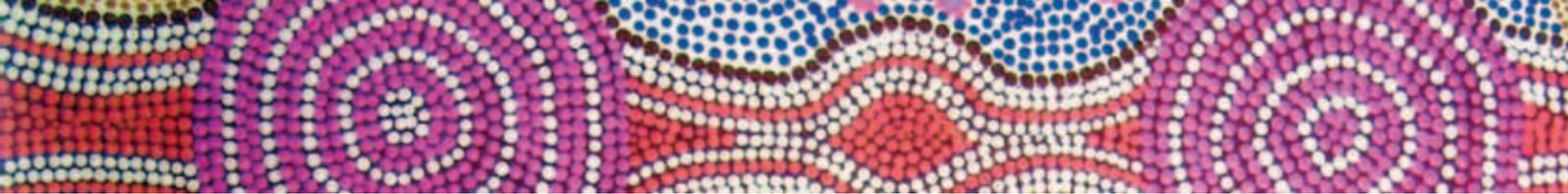




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- 2. What was our research about?**
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- 6. Did this research project help and what changed?**
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1. What is Cancer?

The body is made up of many types of cells. These cells grow and divide in an orderly controlled way to make more cells as they are needed to keep the body healthy. When cells become old or damaged, they die and are replaced with new cells.

Sometimes this orderly process goes wrong. Cancer refers to diseases in which abnormal cells divide without control and are able to invade other tissues. Cancer cells can spread to other parts of the body.

Cancer is not just one disease but many diseases.

Cancer is the biggest killer of non-Aboriginal people and the third largest killer of Aboriginal people after heart disease and injuries from car accidents and self-harm.

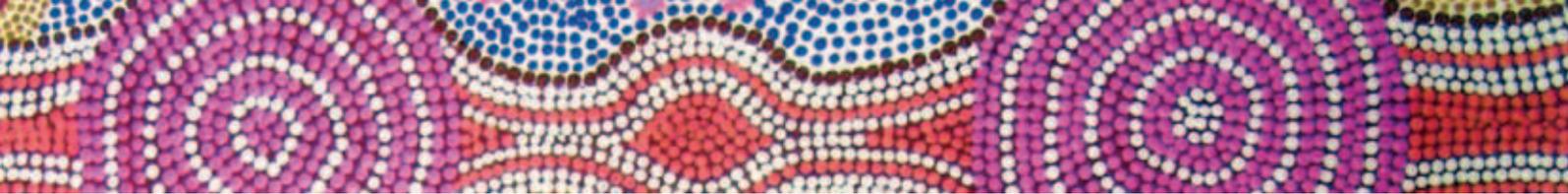
For various reasons, when Aboriginal people get cancer, it is more likely to lead to death than for non-Aboriginal people. Some of these reasons are:

- the stage of cancer is often more advanced by the time it is recognised
- Aboriginal people are less likely to accept and receive adequate treatment
- Aboriginal people get more serious cancers (such as cancers of the lung and liver) that are more likely to be fatal.

Increases in cancer cases and Aboriginal people dying more often because of cancer can be explained in terms of risk through smoking, passive smoking (breathing in tobacco smoke), being overweight and lack of exercise. Many other things such as grief, stress, and poverty can influence these behaviours.

What is worrying is that compared with non-Aboriginal people, even for the same cancer that is diagnosed at about the same stage, Aboriginal people are more likely to have a shorter life expectancy. As researchers, we were interested in finding out why.





2. What was our research about?

Background

This research report was written to give feedback to Aboriginal participants and Aboriginal and non-Aboriginal health care providers about an Aboriginal cancer research project conducted in Western Australia between 2006 and 2009.

Over the past 30 or 40 years, treatments for cancer have improved and these days many people who are diagnosed with cancer are successfully treated and live without cancer for many years after treatment.

Aboriginal Australians are diagnosed with cancer less frequently than non-Aboriginal people. However, Aboriginal people generally experience poorer outcomes from cancer compared with the non-Aboriginal population. Before this research was done, some reasons for these differences were known, including that Aboriginal people are not screened for cancer as much as non-Aboriginal people, so some cancers are diagnosed later at a more advanced stage. It was also known that Aboriginal people may be less willing to start or to get to the end of a full cancer treatment.

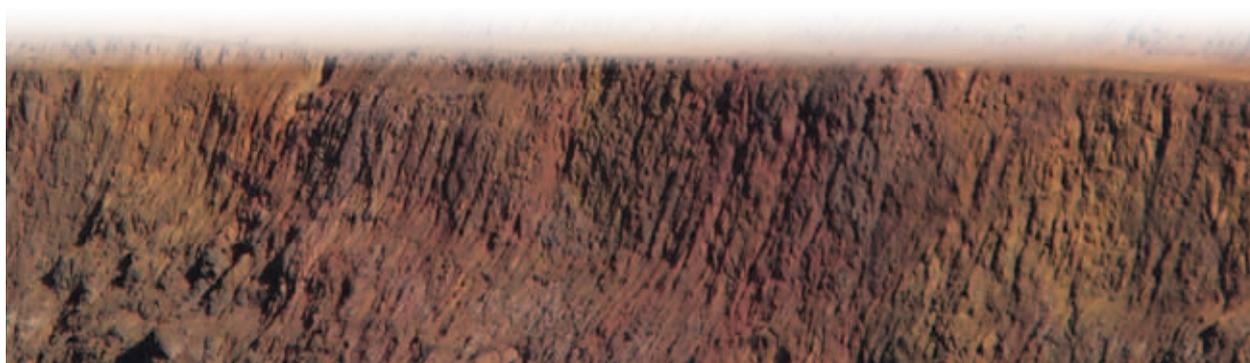
The purpose of this research was to find out more about the reasons for poorer Aboriginal outcomes following a diagnosis of cancer.

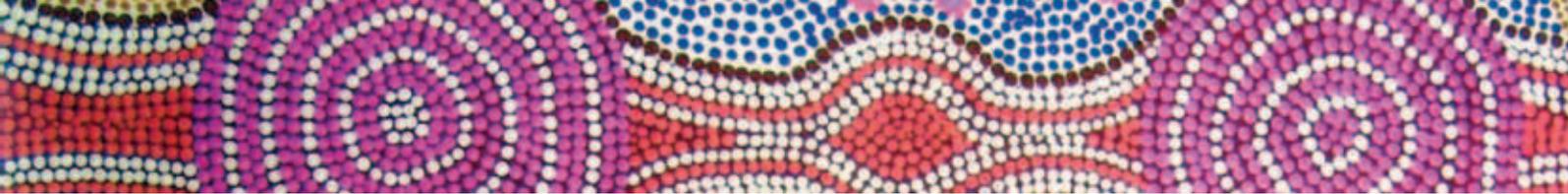
Topics covered by the research

The research found out about Aboriginal people's experiences of cancer, including:

- Beliefs about cancer and ways in which beliefs affected how people sought medical care
- Experiences of the health system during diagnosis and treatment for cancer
- Experiences of communicating with doctors and other health professionals about cancer
- The use of bush medicine and traditional therapies for cancer

The research also looked at what has been written about the beliefs and experiences of cancer amongst Indigenous people in Canada, New Zealand and the United States of America and compared them to Australian Aboriginal beliefs and experiences.





3. How did we do the research?

The research involved 30 interviews with Aboriginal cancer patients, or family members of people who had died from cancer, as well as some Aboriginal health care providers. Those interviewed were men and women who came from various parts of Western Australia.

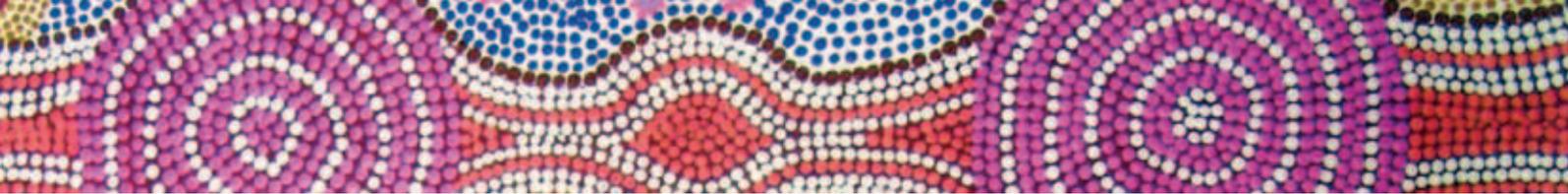
Information was also taken from many published papers and reports.

Approval was received from the WA Aboriginal Health Information and Ethics Committee before the research started.

Members of an Aboriginal Reference Group helped with advice throughout the research, including in the interpretation of information.

The researchers did their best to ensure the research was relationship-based, respectful, culturally appropriate and inclusive of Aboriginal people. They also made sure that the findings of the research were passed on and published so that what was learnt could lead to improvements in the health system and be used by others elsewhere. This information now contributes to the understanding of issues related to Aboriginal people with cancer, which is needed to improve Aboriginal cancer outcomes.





4. What did we find out?

4.1 Aboriginal people's beliefs about cancer

The research found lots of different views about cancer amongst Aboriginal people in WA, which is not surprising given the diversity of Aboriginal people across the State.

Some Aboriginal people have misunderstandings about cancer. The success of treatments for some cancers is not widely known. Some people incorrectly believe that cancer is always a terminal illness, or a 'death sentence'. A fear about cancer means people may prefer to 'not know'. They may avoid going to the doctor when they notice symptoms, or avoid cancer screening when they are well for fear of finding they have cancer. This is not necessarily different from the beliefs and behaviours of many other Australians and people from other cultures.

In some cases the medical system is seen to be all-powerful and thought to be capable of curing everything. Then, when someone dies or the cancer comes back they may be greatly disappointed in doctors and the medical system. Personal stories of a person's bad experiences with the health system are shared in the community, and so people may decide not to have a check up when they notice something wrong, or not to have treatment for cancer.

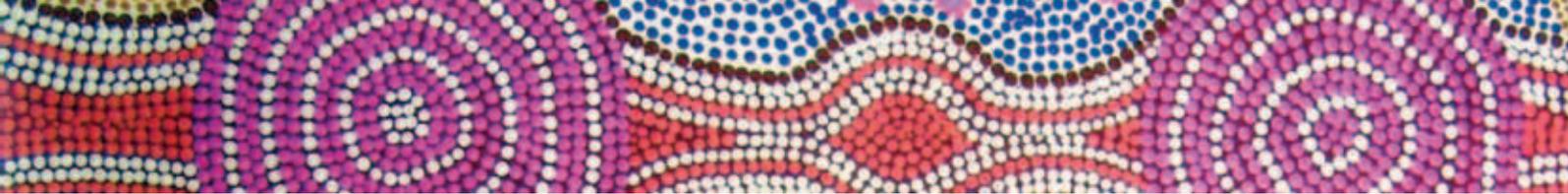
Another belief that influenced people's decisions was that getting cancer was seen as part of their fate or a result of a curse so there was no point in seeking Western treatment.

People reported feeling shame around cancer screening and diagnosis. Some Aboriginal community members fear that cancer is contagious and they could catch it or transmit it to others.

"...it was almost like you deserved it or there was definitely this sense of shame. It was whispered. If someone died of a heart attack you would say that, but... all this cancer stuff was a whispered sort of stuff." (Research participant)

Fatalism (or a belief that nothing you can do will make a difference), shame and fear are some of the reasons why people avoid cancer screening, ignore symptoms or avoid seeking treatment after they have been diagnosed. Some people fear having to leave their family, community and country and some believe that "when people go to Perth, they come back in a box." Sadly, when people put off seeking help, their cancer may progress too far for it to be cured or have successful treatment that prolongs their life.

There is a need for more education about symptoms of cancer and the need for people to seek medical advice early, before the cancer takes a strong hold.



Cancer is widely feared across the Aboriginal population and these fears are also found amongst non-Aboriginal people. However, Aboriginal people are often diagnosed when their cancer is more advanced, so stories about successful treatment and survival are less common. Sometimes when people have cancer, they are reluctant to talk about it for various reasons of which one is feeling shame. This means that by keeping quiet they can miss out on the help and support that is available. When they are treated successfully and or even cured, their stories often don't get told in the community so people don't hear about alternative views of the cancer experience. This means that the negative view of cancer continues, with misunderstandings and fear persisting.

Through better information about successful cancer treatments and stories of survival, fatalistic attitudes and beliefs could be changed.

4.2 Aboriginal people's experiences of cancer

While some people reported helpful and positive experiences of the health system, others did not.

Transport, accommodation, the hospital environment, the cost of medicines and treatments and communication with doctors and other health professionals were areas which presented difficulties in dealing with cancer.

Transport

The need to travel to Perth for treatment can pose a big problem for many patients.

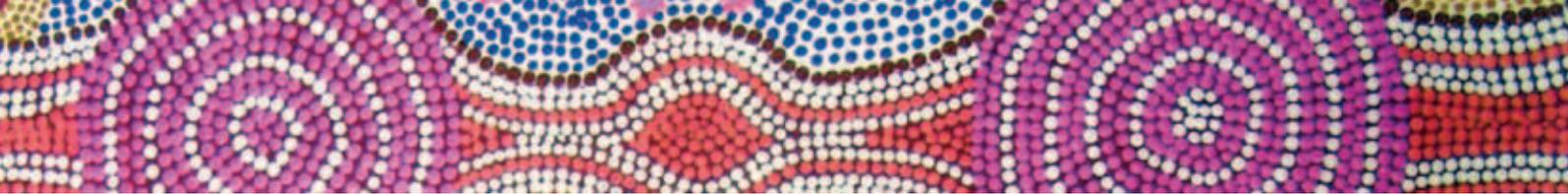
Although some participants received support from the Patient Assisted Travel Scheme (PATS) which covered part of their travel costs, many Aboriginal people found the PATS system complicated and were unclear about what costs were covered by PATS and what costs were not. Many rural participants had difficulties dealing with the travel system.

People living in remote areas often have no experience of the city and find going to Perth an overwhelming experience. Older and more traditional people may decide they don't want to leave their community to access the treatment they need:

"People think 'no I don't want to go down because I've got no way of getting there, going to the hospital, or I don't have any family down there', so they choose not to"
(Research participant).

Rural residents often did not realise the distances, cost of taxis, parking and other needs related to accessing treatment in the city. These additional costs quickly used up the money for food and accommodation.

The Aboriginal population in Perth who often live in outer urban areas also need to travel for treatment. They do not receive money for their travel costs.



Accommodation

Sometimes referral arrangements were poor, with the hospital unaware that someone was arriving for treatment. At times accommodation arrangements were not made and people felt unsafe and uncomfortable with the bookings that had been made. Aboriginal patients felt they sometimes got “lost in the system”, both for their initial and follow-up treatments.

Hostel accommodation can be unfamiliar and confronting. One participant reported she had refused to stay in an Aboriginal hostel as she didn’t know the hostel residents; they were strangers. Some worried about security at the hostel.

Some patients stopped treatment if their accommodation didn’t work out. They did not use hospital support to solve the accommodation problem because they didn’t know and hadn’t been told how to do so:

“Because a lot of people when they get here and have got nowhere to room, they like to wait until the next morning and go back. They don’t even know about people like in the social worker side because nobody told them” (Research participant).

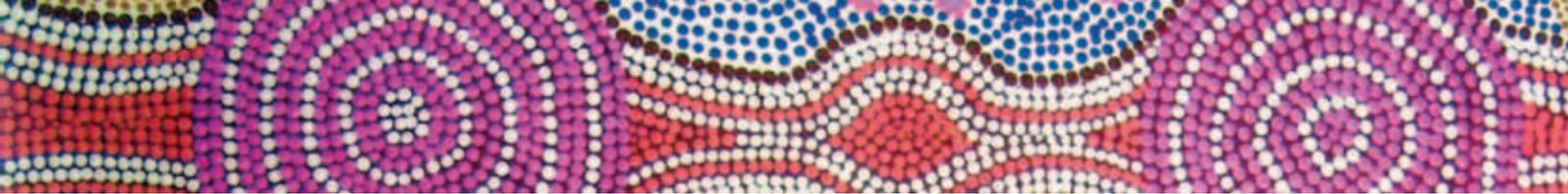
Hostels were not always close to shops. If people were feeling weak or unwell and didn’t have a car, this posed big problems.

For women with children, having to travel for treatment was difficult. One woman whose child had to go to hospital in Perth for cancer treatment had four other children who had to travel with her. She couldn’t leave them behind in the community because her husband was in jail and there was no-one else in the community to look after them for that length of time. She had to take her children out of school to make the trip. Once in Perth, because she couldn’t drive, it was difficult making trips to the hospital to visit her child. Lack of childcare facilities for people visiting adults in hospitals in Perth made it difficult for people to support their family member.

The hospital environment

“Unless you can read...I am lucky I have learned, but some of the elders and some young people who are stressed out and walking around trying to find B block [in the hospital] or whatever, the radiation centre...yeah, it’s hard... you can’t find the place” (Research participant).

Many participants described the hospital environment as unfriendly and confusing. Some participants reported they were just given a map of a big hospital which was like being in a strange city. It was difficult for them to find their way around and even harder if they couldn’t read the signs. One participant spoke about accompanying her father to a city hospital, “one big grey building”, and how they had both felt like crying. Another participant was terrified of lifts and wouldn’t get into them on her own. She had to climb flights of stairs and felt unwell going from one floor to another.



It was uncomfortable for a number of Aboriginal patients to step into Noongar country without any formal welcome or invitation. Patients come to the hospitals in Perth referred by a medical professional, often in a way that occurs quickly and unexpectedly. Travelling across country in a responsible way is important in Aboriginal culture as it ensures that visitors are respecting the host and the country they visit.

Hospital food which was unfamiliar was also an issue:

"There was the food - a lot of them don't eat vegetables and what you get on the plate. A lot of them would ask for kangaroo, 'Is kangaroo going to be served?'"
(Research participant)

Older Aboriginal men seemed to find the hospital system and dependency particularly disempowering. One participant said her 84-year old grandfather "hated being heavily dependent on strangers" in hospital. He was a proud, independent man who disliked having to ask for things when he needed them. He hated being restricted to bed and detested the food.

Embarrassment about invasion of privacy in hospital caused shame and discomfort for some Aboriginal patients. People mentioned teaching sessions with medical students and ward rounds:

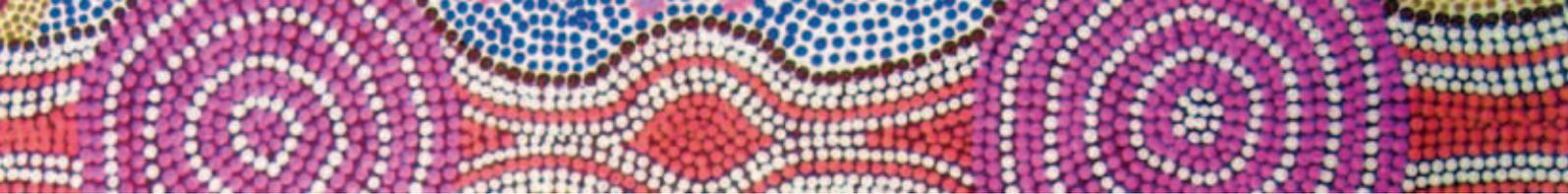
"...just having those ten people all staring down at you like this, that is intimidating enough in itself. So, I don't know that people would feel that comfortable with asking personal questions about their private life, their personal body parts" (Research participant)

Perhaps one of the greatest difficulties experienced was the lack of flexibility in hospitals when the extended family visited. Sometimes hospital staff had restricted the number of people allowed in a ward room. This was particularly hard for extended family when a relative was dying or had died:

"...that's our culture. Like when someone is close to passing away the whole extended family will come. That's been like that for years. You can't change that... they want the whole family to come in..." (Research participant)

Costs of medicines and treatments

Many cancer treatments are expensive and either unavailable or have long waiting lists in the public system. Aboriginal people in WA have much lower rates of private health insurance, so they are less likely to be able to access services available to private patients.



One participant described how her sister had continued working so she could afford cancer medication up until the time she couldn't work anymore. Once on a pension she was entitled to subsidised medication, but even then it was very expensive. Ultimately, the participant started paying for her sister's medication on her credit card because she could not afford to get it any other way.

If people think they cannot afford the treatment and cost of travel, they may avoid the embarrassment and shame of admitting their financial difficulties by choosing not to take up treatment.

Communication

Misunderstandings were common particularly with the use of medical language which was mysterious and confusing; people wanted more time and attention to careful explanations. Health providers also need to understand and pay attention to Aboriginal people's non-verbal behaviour. When health staff are unable to interpret non-verbal communication and don't recognise that hospital environments can be overwhelming and intimidating, the health care they provide won't meet the patient's needs and it is the patient and their family who suffer.

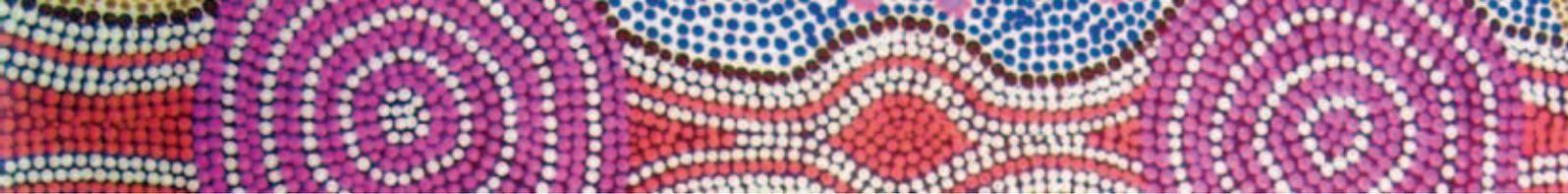
In addition, health care providers didn't always recognise the importance of family and country to Aboriginal people. This can have a big impact on people's decisions to move away from home for treatment. Aboriginal people wanted to have care provided closer to home when possible. They particularly disliked having to travel a long way for a short chat, a cursory check-up or the doctor just looking at their results on a computer screen. Sometimes doctors seemed not to realise how far they had travelled, how long they had waited and how difficult it had been for them to get there.

Another area where the health care system can improve is in recognising the holistic approach (physical, mental, emotional and spiritual) to healing and well-being. Aboriginal people place a high value on this holistic approach and it can affect their decisions around cancer screening, diagnosis and treatment. Aboriginal people often see that individual, family and community are inseparable and that all these areas need to be looked after for people to seek healthcare.

Aboriginal staff

"Especially a lot of people when they come from the community, they don't know what they are gonna face. Yeah, like...where are they gonna stay, how they are gonna support themselves for six weeks, and if their family is gonna come. ...A lot of support should come from within the hospital as well, especially social workers."
(Research participant)

Many participants reported how hard it was for Aboriginal patients to leave their communities for the first time and travel to a city without family, and to a place where they knew no one. However, the rules of health services, the cost of travel and family responsibilities meant sometimes that a family member couldn't accompany them.



Participants mentioned the need for an Aboriginal Liaison Officer or other Aboriginal worker to give direct practical and emotional support to Aboriginal patients and families, especially important for people from rural and remote areas. They needed someone to provide information and make them feel more comfortable about the whole process of cancer treatment. Information from an Aboriginal person explaining the treatment program was needed before people travelled to Perth. There was a need to:

"...come down to their level about these issues like cancer and tell them...talk at their level that they can understand. This is what you are going to face...when you go to the big city. Don't be frightened" (Research participant)

Back in their home communities after having cancer treatment, Aboriginal people found it hard to access follow-up support such as counselling or physiotherapy, or to get practical information on issues like post-cancer treatment, lifestyle and diet. Aboriginal liaison workers in the community were suggested to help connect patients with services and give culturally appropriate information.

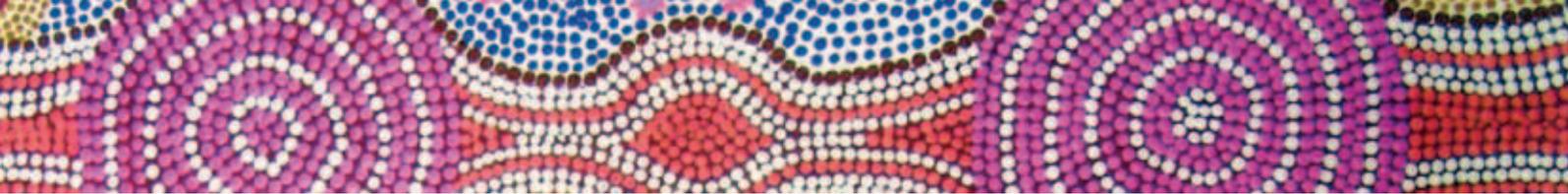
Another issue was communication breakdowns between local hospitals or clinics and the treatment hospitals in Perth. Sometimes appointments were made by the Perth hospital for treatment and follow-up with little understanding of where the person lived, and the time and expense of travel. Involving the local doctor or clinic before making the appointment could have helped to get support for the patient to attend follow-up appointments.

Positive support experiences

Some people reported they had positive experiences with issues such as transport and care. Payment by PATS for an airfare or fuel costs and contribution towards accommodation costs were mentioned. Other participants, especially those from rural and remote areas, praised palliative care and home-nursing services. Participants appreciated the providers' warmth, friendliness and caring behaviour. They remarked on their willingness to spend time with the patient and family when visiting and their attention to detail when discussing issues that could arise:

"The Silver Chain external nursing agency... they were very good and helpful...more supportive and friendly...the medication and stuff that they ensured over the first couple of weeks so that we knew exactly when to do it and all that ...they were brilliant" (Research participant).

Other support services that were mentioned positively included local Aboriginal Medical Services, access to wigs from the Cancer Council and Disability Services putting in amenities to help patients affected by treatment or illness.



A few participants talked about getting lots of support from the Social Work department within the hospitals, such as arranging accommodation, maintaining links with family during treatment, access to discounted food supplies and assistance with returning home. It seemed that families who had connections with the health system because someone worked in health were most likely to know about and benefit from such services. Many Aboriginal participants did not ask for support services because they did not know about them, or because they were afraid to ask. Unfortunately this often meant they did not receive the help they could have had.

Use of bush medicines

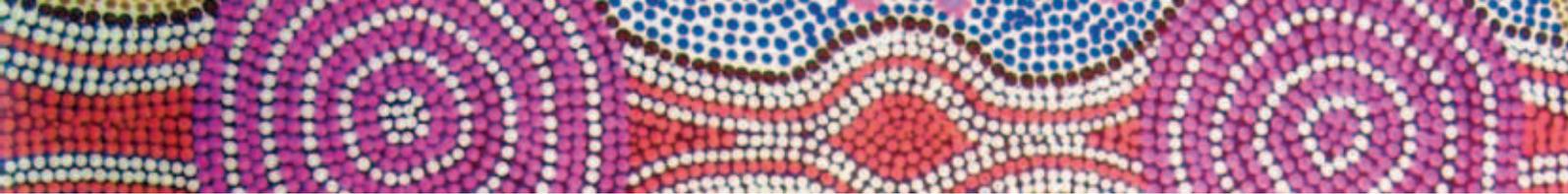
Many Aboriginal patients with cancer who were interviewed had used bush medicine either at the same time as taking Western medicines or following chemotherapy and radiotherapy. "Healing is not just physical; it's mental, emotional and spiritual as well", and bush medicine was seen as part of a holistic approach:

"There is something in it...that is good for your insides, just as a cleanser. Makes all your body organs healthy and strong, it gets rid of all your internal stress" (Research participant).

Participants also emphasized the importance of cancer being diagnosed at an early stage for bush medicine to work. Even when cure was not possible, bush medicine was used for well-being because it helped to reconnect cancer sufferers with their heritage, land, culture and the spirits of their ancestors, bringing peace of mind during their illness.

Many participants said it was hard to get bush medicine. Some stated that getting the medicine from a traditional healer was important and that their permission was needed to collect the plants used for treating cancer, to be told where and when to harvest it, how to prepare the medicine and how and when to take it. For this to happen, the person should have a good relationship with the healer. Since most traditional healers live in rural and remote areas, it was hard to access bush medicine and other traditional methods.





5. Recommendations from the research

Aboriginal Community education

- More stories and testimonies from Aboriginal cancer survivors need to be told and circulated in Aboriginal communities.
- Community education needs to focus on the importance of early diagnosis and recognising symptoms.
- Both general information and information about specific cancers is needed.
- Explore alternative means and media for promoting cancer prevention and increase understanding of cancer treatments.

The Health System

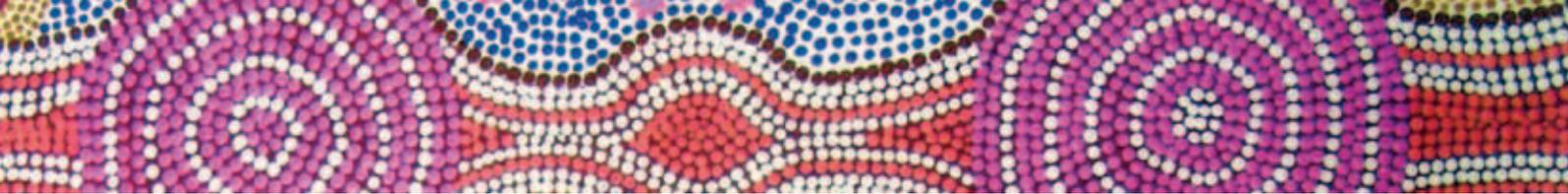
- Case conferencing (either by video or telephone) between cancer specialists, doctors, Aboriginal Health Workers and other primary care providers would be useful for coordination and developing a better understanding amongst all parties of issues related to an individual's treatment and care.

Transfer of Care

- Improve planning around discharge through communication with all relevant stakeholders.
- Develop systems that support improved linkages back with primary care services.
- Ensure ongoing access to appropriate psychosocial support with an emphasis on enhancing well-being.

Hospital Environment

- Improve the hospital environment and make it welcoming for Aboriginal people by providing a culturally secure environment (through welcome to country services, Aboriginal staff, Aboriginal artwork, opportunities for painting, yarning places, access to traditional foods, access to outdoor gardens).
- Facilitate return of Aboriginal patients to their homeland for continued care where possible.
- Develop an effective and efficient coordination process that involves the hospital, the patient and their family, and primary care provider.
- Ensure that there is access to Aboriginal interpreters for Aboriginal people who are not confident speakers of English, and that staff understand differences in Aboriginal communication styles.



Professional education

- Health service providers need to develop skills to be culturally sensitive and empathic so they can communicate and care for Aboriginal people better in the hospital setting. Those skills include understanding non-verbal communication, and the importance of interconnectness of history, family, land and community.
- Service providers also need to be familiar with, acknowledge and respect Aboriginal family structures, culture and life circumstances.
- Service providers need to understand the existence of Aboriginal knowledge and accept that traditional methods can be an important addition to an Aboriginal person's healing, in addition to Western medical treatments and care.

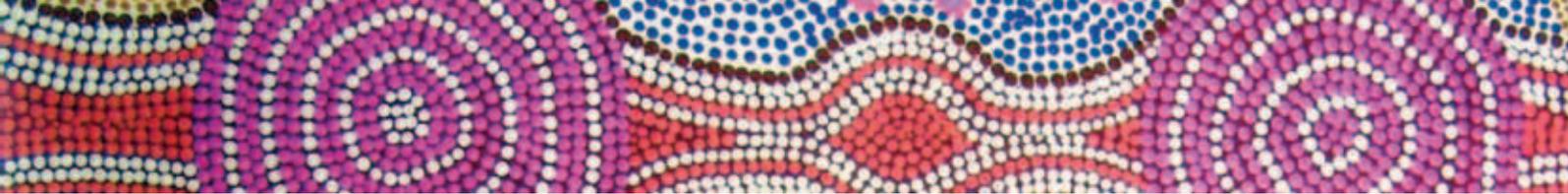
Support services

Transport

- Increase the awareness of health service providers about the impact that distance and travel is likely to have on their patients.
- PATS program to be better promoted and entitlements made clearer to users.
- The process of claiming PATS should be simplified and made easier to understand.
- Ensure workable arrangements that support travel of patients and accompanying persons for necessary travel while in the metropolitan area.
- Establish cancer services in outer urban and large regional centres if feasible.
- Reduce the need to travel when possible through alternative ways of follow-up such as wound checks and minor follow up undertaken via video conferencing or telehealth or at a local health service.
- Increase outreach delivery of specialist care in community-based services to overcome some of the barriers relating to distance, communication and cultural appropriateness of services.
- Consult with Noongar elders about the most appropriate method to welcome patients to country. This could take the form of a DVD for example. The DVD could have a recorded welcome to country along with other information about the hospital, Perth, transport or services that are available.

Accommodation

- Ensure provision of adequate and culturally safe accommodation facilities that are easily accessible to treatment services and offer adequate safety and support.
- Recognise the importance for Aboriginal people of family members being able to stay with them and provide support.

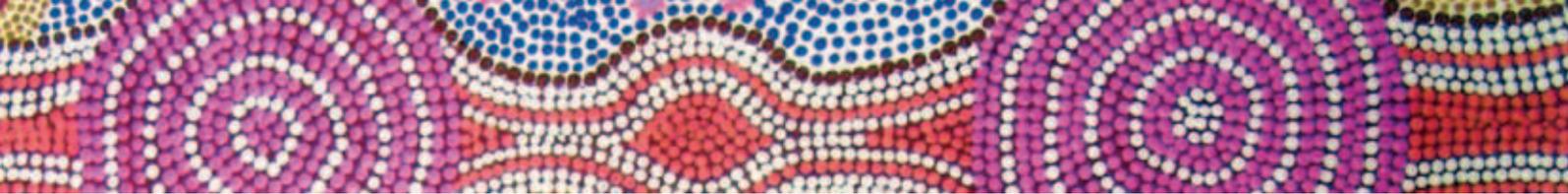


- Ensure patient support services have a welcoming atmosphere and take immediate initiatives in attending to the needs of Aboriginal patients.
- Recognise the need for patients in self-catering facilities to have access to shops and transport and encourage the availability of healthy traditional foods.

Aboriginal Support and Liaison

- Employ more Aboriginal health workers in hospitals, and invite Aboriginal people to participate at a decision-making levels within hospitals.
- Consider patient advocates or navigators to provide support and assistance to the patient and their family in negotiating the health and hospital system.
- Where possible it is important to ensure the support of a trusted, caring family member who can assist a patient with finding their way to and within the hospital.
- Provide information and help with accessing relevant support agencies. One possibility is that a support kit is developed that can be handed to Aboriginal patients travelling to or arriving in Perth. This kit could have all the information in it about discount food supplies and contain vouchers, bus routes, and contact information.





6. Did this research project help and what changed?

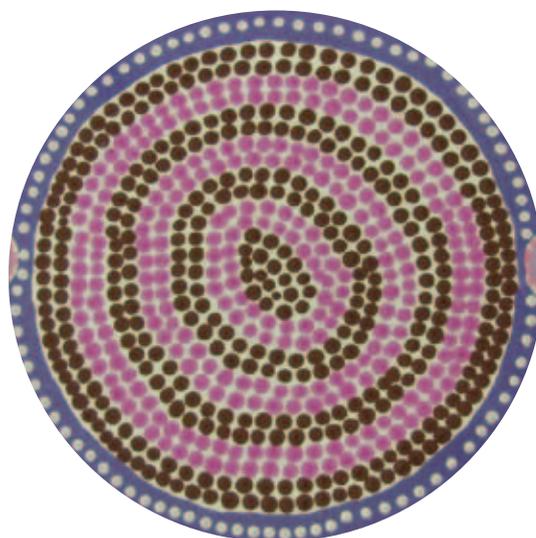
Lots of things have changed since this project commenced. At a broader political level, the Apology by the Federal government and the launching of the Close the Gap measures have taken place. That means that the information from the research is likely to be used to inform changing the approaches and way services are delivered. We have made lots of recommendations!

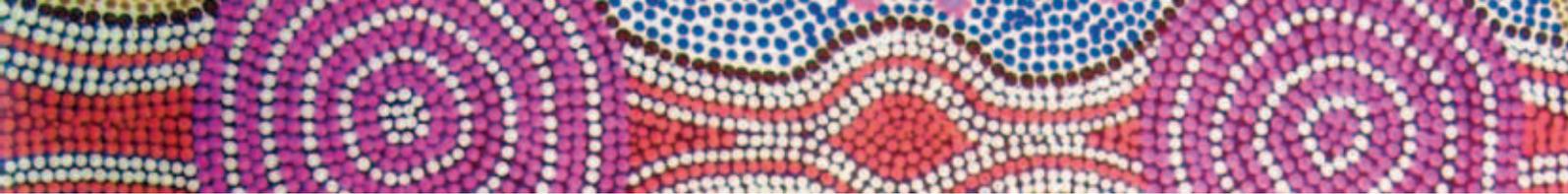
As a research outcome, the researchers have put a lot of effort into disseminating information about the research to people involved in cancer planning and care. This has been through writing papers in journals, presentations at scientific meetings, presenting in Aboriginal health forums, teaching sessions to health students and health service providers, working on committees, and reporting back to the Aboriginal reference group and community members.

The information has been passed on to others so that there will be more awareness of the problems that Aboriginal people face.

More Aboriginal people are now interested in doing something about cancer. There are two Aboriginal people in Western Australia who have now started to do their own research to get more information.

Another outcome of the project was the development of a support group for Aboriginal women with cancer in the Midwest region of WA. The Indigenous Women's Cancer Network operates to provide emotional support and practical help directly to Indigenous people with cancer. It plays an important role in overcoming communication and other cultural barriers to accessing cancer treatment. Aboriginal support groups may be a good way to develop effective partnerships between Aboriginal people and non-Aboriginal health service providers.

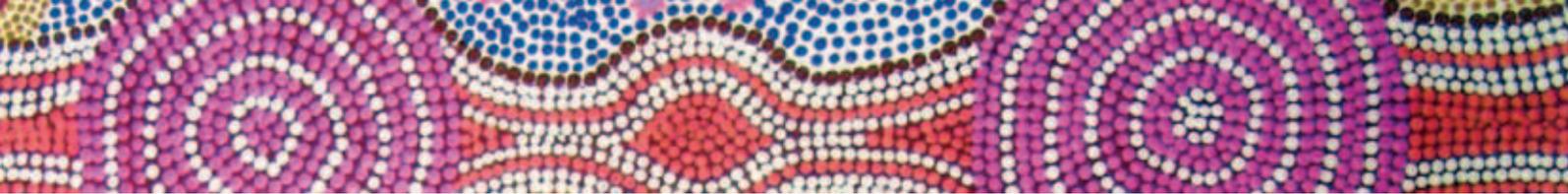




This quote from an e-mail from an Aboriginal friend and colleague of the researchers shows how health service providers are providing culturally sensitive care - we like to think our research and the efforts of many other are contributing to better health care for Aboriginal people.

It is a very trying time but with each other's support we are all coping with our loss. It was very sudden. He was in RPH and the sisters and doctors and other staff were very kind and considerate to my brother and all his visitors. We couldn't fault their treatment of our brother and uncle and their care of him was really gratifying to see. The doctors and head sister who spoke to us about his condition was up front with us. They spoke to all the family in such a caring manner and made him as comfortable as possible; even to the point that they gave him a private room and set up a camp bed so that Leanne and his son took turns staying with him overnight to make sure there was someone with him all the time. They also took into account that he had so many relatives and friends who wanted to say their goodbyes to him and they didn't mind all these blackfellas coming and going all the time. They even gave my brother a male nurse to see to his personal care when he asked for one. Their care of him was beyond reproach and I can't praise the staff on Ward 9 enough. I wrote and told them so too.

Rosemary van den Berg
(15 July 2010)
[Attributed with her permission]



7. Peer-reviewed publications

Finn L, Pepper A, Gregory P, Thompson SC. Improving Indigenous access to cancer screening and treatment services: descriptive findings and a preliminary report on the Midwest Indigenous Women's Cancer Support Group. *AMJ* 2008;1, 1-21. doi:10.4066/amj.2008.31

<http://www.amj.net.au/index.php?journal=AMJ&page=article&op=viewFile&path%5B%5D=31&path%5B%5D=122>

Shahid S, Thompson SC. An overview of Indigenous cancer and their beliefs around the disease, a cross-country comparison: Australia, Canada, New Zealand and the United States. *Aust NZ J Public Health* 2009; 33:109-18.

Shahid S, Finn L, Thompson SC. Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting. *Med J Aust* 2009; 190: 574-579.

Shahid S, Finn L, Bessarab D, Thompson SC. Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. *BMC Health Services Research* 2009; 9:132.

<http://www.biomedcentral.com/content/pdf/1472-6963-9-132.pdf>

Shahid S, Bessarab D, Howat P, Thompson SC. Exploration of the beliefs and experiences of Aboriginal people with cancer in Western Australia: A methodology to acknowledge cultural difference and build understanding. *BMC Medical Research Methodology* 2009, 9:60

<http://www.biomedcentral.com/content/pdf/1471-2288-9-60.pdf>

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 Ethnomed.* 2010 Jun 23;6(1):18.

<http://www.ethnobiomed.com/content/6/1/18>

Christou A, Katzenellenbogen J, Thompson SC. Australia's National Bowel Cancer Screening Program: does it work for Indigenous Australians? *BMC Public Health* 2010 Jun 25;10(1):373.

<http://www.biomedcentral.com/content/pdf/1471-2458-10-373.pdf>

Shahid S, Finn L, Bessarab D, Thompson SC. Nowhere to room? nobody told them": Logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment. *Aust Health Review* 2011;35 (2). DOI: 10.1071/AH09835

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, 4:62. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3068108/pdf/1756-0500-4-62.pdf>

