

**Centre for International Health**

**Towards Understanding Disparities in Cancer Outcomes for  
Aboriginal Australians: Exploring Aboriginal Perceptions and  
Experiences of Cancer in Western Australia**

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## **Declaration**

This thesis does not contain any material which has been presented or accepted for the award of any other degree or diploma in any other university. This contains no material previously published by any other person except where due acknowledgement has been made.

This thesis is the author's original work and was undertaken by the author with the acknowledgement of the contributions of other authors as stated. The study proposal, ethics approval, data analysis, writing the thesis and published papers were undertaken with the primary supervision of Winthrop Professor Sandra C. Thompson.

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Signature:

Date: .....

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## **Abstract**

Cancer has become one of the major chronic diseases among Aboriginal and Torres Strait Islander people of Australia, and was declared a health priority in the National Aboriginal and Torres Strait Islander Health Strategy in 2001. Since then efforts have been instigated to improve the epidemiological information with regard to cancer among Aboriginal Australians in several jurisdictions. Specific issues related to cancer have been identified. Aboriginal Australians compared with non-Aboriginal people have higher occurrence of preventable cancers and are less likely to access cancer screening, are diagnosed at a more advanced stage, have poor continuity of care, lower compliance with treatment and lower five-year survival rates. Several risk factors for higher incidence of some cancers have also been noted. However, these do not adequately explain the reasons behind the delayed presentation, poor compliance and different treatment outcomes of cancer among Aboriginal Australians compared to the total population.

To investigate and explore the variations in Aboriginal Australians' beliefs, understanding and perceptions around cancer and their experiences with cancer services, an exploratory, in-depth qualitative study was undertaken in several locations of Western Australia (WA). This was done with a view to understanding Aboriginal decision-making processes in relation to accessing cancer care in WA. The study was approved by the Human Research Ethics Committee (HREC) of Curtin University, the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC), the Royal Perth and Sir Charles Gairdner Hospitals, and by the local Aboriginal Community Controlled Health Services (ACCHS) in regions where the research was conducted.

The study adopted a hermeneutic phenomenological research design and used qualitative methods. A hermeneutic phenomenological approach was chosen as this allowed understanding to emerge from the experiences of the participants through interpreting the situated meaning of humans in the world. The views of 30 Aboriginal participants – including patients, survivors and close family members who had lost someone to cancer in their families – were gathered through in-depth

interviews. The fieldwork was conducted between March 2006 and September 2007. Interview data were tape-recorded, transcribed and analysed using NVivo7 Software. Thematic analysis was carried out from the information.

The findings from the study suggest that many factors affect Aboriginal people's willingness and ability to participate in cancer-related screening and treatment services. Late diagnoses were not only due to late presentations, as some delayed diagnoses occurred in patients who had regular contact with medical services. Participation in treatment is affected by beliefs and fatalistic attitudes towards cancer; limited understanding of the biomedical aspects of cancer and treatment processes; preference of Aboriginal people to use other approaches to healing such as traditional healers and bush medicine; unwillingness to be separated from family and country, and several infrastructural and logistical issues such as cost, transport and accommodation. It was found that fear of death, shame, beliefs such as cancer is contagious and other spiritual issues affected Aboriginal people's decisions around accessing services.

Moreover, miscommunication between Aboriginal patients and health care providers, lack of cultural security and culturally appropriate support services, lack of Aboriginal staff within the hospital to personally support Aboriginal patients, and the alienating environment of oncology treatment services were also mentioned as barriers. Factors important for effective patient-provider communication such as language, shared understanding, knowledge and use of medical terminology require particular attention. Lack of a reliable and on-going relationship with service providers also came up quite persistently. All of these issues were underpinned by the historical context which includes past discriminatory treatment and experiences of racism by Aboriginal people within mainstream medical institutions. These factors contribute to fear of the medical system, feelings of disempowerment, and mistrust towards the system which constrain Aboriginal participation in cancer treatment and other support services.

The results of this study indicate that an understanding of the complex “layers” (from micro to macro) of factors and the interactions between them is required to elucidate Aboriginal people’s decision-making processes around engaging and participating in mainstream cancer services. This research identified gaps in knowledge and understanding and a lack of support services within Aboriginal communities.

The findings from the research have been shared with relevant cancer-specific and Aboriginal Community Controlled Health Services with a vision to utilise the study outcomes for the benefit of Aboriginal individuals and communities. Aboriginal people were invited to be co-presenters and co-authors wherever the study findings were presented. An Indigenous Women’s Cancer Support Group (IWCSG) was established in Geraldton after the completion of fieldwork there. This support group has been working to raise awareness of cancer in local Aboriginal people.

Some suggestions and recommendations to improve services and cancer outcomes for Aboriginal Australians came out of the study. These include: employment of Aboriginal staff in services and involvement of them in decision-making, maintenance of culturally sensitive, empathetic person-to-person contact, provision of infrastructural and institutional support to involve Aboriginal families within the treatment domain; acknowledgement of holistic concepts of health and well-being; and increase Aboriginal health literacy with regard to cancer.



## **Acknowledgements**

I am obliged to many people in the journey of my doctoral thesis. First and foremost is my Supervisor Winthrop Professor Sandra Thompson. No words would be enough to thank her for her continuous guidance and patience, perspicacity, kind, friendly and cordial support. Her passion, dedication and commitment to improve Aboriginal health and overall well-being inspired me throughout this study. I am grateful for her time and suggestions during this whole period of research and during the writing of this thesis. She is a tireless motivator, and her continuous guidance and encouragement helped me to develop my ability to complete a research work more efficiently and increased my confidence in writing.

My thanks go to my Associate Supervisor, Associate Professor Dawn Bessarab. She has taught me a number of practical aspects of conducting Indigenous research that have boosted my confidence about working with Aboriginal communities in effective, appropriate and culturally sensitive ways. Her knowledge and critical thinking has been an inspiration to me throughout.

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I would like to thank the Aboriginal Reference Group members for their invaluable contribution at different phases of the project: Leanne Pilkington, Francine Eades, John Mallard, Dot Henry, Gwen Rakabula and Michael Doyle. This research was supported by a grant from the Cancer Council of Western Australia. I would like to acknowledge the contribution of the other investigators: Peter Howat, Brian Bishop, Timothy Threlfall, Katie Thomas, Moyez Jiwa, John Mallard, Terry Slevin, Leanne Pilkington, Francine Eades, Dot Henry, Gwen Rakabula, Dawn Bessarab, Jude Comfort and Kim Worthington.

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## Abbreviations

AACR	Australasian Association of cancer Registries
ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
ACCU	Aboriginal Cancer Care Unit
AHCWA	Aboriginal Health Council of Western Australia
AH&MRC	Aboriginal Health and Medical Research Council
AHWs	Aboriginal Health Workers
AIAN	American Indian and Alaska Natives
AIHW	Australian Institute of Health and Welfare
ALO	Aboriginal Liaison Officer
AMS	Aboriginal Medical Services
ARG	Aboriginal Reference Group
CIRTS	Curtin International Research Tuition Scholarship
DIA	Department of Indigenous Affairs
DMOs	District Medical Officers
FNs	First Nations
GP	General Practitioner
HBV	Hepatitis B virus
HPV	Human Papillomavirus
HREC	Human research Ethics Committee
IHS	Indian Health Services
IWCSG	Indigenous Women's Cancer Support Group
NACCHO	National Aboriginal Community Controlled Health Organisation
NAIDOC	National Aborigines and Islanders Day Observance Committee

NCSP	National Cervical Screening Programme
NHL	Non-Hodgkin's Lymphoma
NHMRC	National Health and Medical Research Council
NSW	New South Wales
NT	Northern Territory
PACS	Picture Archiving Compression System
PEPA	Program of Experience in the Palliative Approach
PSA	Prostate-Specific Antigen
RANs	Remote Area Nurses
SA	South Australia
SEER	Surveillance, Epidemiology and End Results
TCCWA	The Cancer Council of Western Australia
UK	United Kingdom
US	United States
WA	Western Australia
WAAHIEC	Western Australian Health Information and Ethics Committee

## List of Included Publications

**Shahid, S.,** Finn, L., Bessarab, D., Thompson, S.C. (Accepted) “*Nowhere to room...nobody told them*”: Aboriginal peoples’ views on logistical impediments to participation in cancer treatment. Accepted by the Australian Health Review

**Shahid S,** Blears R, Bessarab D, Thompson SC (2010). “*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.* 6 (18).

**Shahid S,** Bessarab D, Howat P, Thompson SC (2009). 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.* 9(60).

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

**Shahid S,** Finn L, Thompson SC (2009). Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting. *The Medical Journal of Australia.* 190 (10): 574-579.

**Shahid S,** Thompson SC (2009). An overview of Indigenous cancer and their beliefs around the disease, a cross-country comparison: Australia, Canada, New Zealand and the United States. *Australian and New Zealand Journal of Public Health.* 33 (2): 109-118.

**Shahid S, Beckmann KR, Thompson SC (2008).** Supporting cancer control for Indigenous Australians: initiatives and challenges for Cancer Councils in Australia. *Australian Health Review.*32 (1): 56-65.

## Conference Presentations

**Shahid, S.** Barriers to participation of Aboriginal people in cancer care. Western Australian Center for Cancer & Palliative Care, 9 August, 2010, Perth, Western Australia.

Thompson SC, **Shahid S.** More ladders than snakes?: reflections on research about Aboriginal people with cancer. WA Cancer Research Symposium, 3 December, 2009, Perth, Western Australia.

**Shahid S,** Pilkington L, Thompson SC. Cancer among Indigenous Australians: An innovative, culturally suitable service delivery design is needed. World Congress of Health Professions Conference, 26-29 March, 2008, Perth, Western Australia.

**Shahid S,** Thompson SC. What does cancer matter?: Aboriginal Australian perspectives on cancer and implications for health service providers. 9<sup>th</sup> World Congress of Psycho-Oncology, 16-20 September, 2007, London, United Kingdom.

**Shahid S,** Thompson SC, Pepper A. Aboriginal Australian perspectives on cancer: implications for health service providers. Public Health Association of Australia Annual Conference, 23-26 September, 2007, Alice Springs, Northern Territory.

**Shahid S.** Experience of Indigenous cancer control around the globe: implications for Australia. 2<sup>nd</sup> Cancer Council Research Symposium, 29 March, 2007, Perth, Western Australia.

Thompson S, Pepper A, **Shahid S,** Gilles M. “From Little Things Big Things Grow”:  
Can research enable better care and support for Indigenous people with cancer?  
CRIA Conference, 2007, Sydney, NSW.

**Shahid S**, Doyle M, Pilkington S, Sharrock P, Merritt G, Beckmann K, Thompson SC. A long way to go: Improving cancer-related outcomes for Aboriginal people in Western Australia. 5th WA State Cancer Conference, Cancer Council Western Australia, 18 October, 2005, Perth, Western Australia.

**Shahid S**. Improving Cancer-related Outcomes in Indigenous Australians. Health Promotion Course, WA Centre for Health Promotion Research, Curtin University, 25 May, 2007, Perth, Western Australia.

**Shahid S**, Thompson SC. Aboriginal views on improving cancer care services: communication in the hospital setting. *Mark Liveris Health Sciences Research Student Seminar*. Division of Health Sciences, Curtin University, 6 November, 2008, Perth, Western Australia.

Thompson SC, **Shahid S**, Finn L. Aboriginal views on improving cancer services: do we care enough to act? WA Cancer Council State Conference, 2008, Perth, Western Australia.

**Shahid S**, Pilkington L, Thompson SC. Cancer among Indigenous Australians: an innovative, culturally suitable service delivery design is needed. Seminar in the King Edward Memorial Hospital, 19 September, 2008, Perth, Western Australia.

**Shahid S**. Barriers to participation of Aboriginal people in cancer care: Communication issues within the hospital setting. WA Cancer & Palliative Care Network on 31 July, 2008, Perth, Western Australia.

**Shahid S**. Aboriginal Australian understanding, beliefs and perspectives on cancer. Doctoral Forum, Centre for International Health, Division of Health Sciences, Curtin University, 3 July 2008, Perth, Western Australia.



**Shahid S**, Thompson SC. Aboriginal people's experiences of cancer. Aboriginal advisory group meeting of Cancer Council, WA, 15 April, 2008, Perth, Western Australia.

**Shahid, S**, Thompson, SC. Cancer among Indigenous Australians: An innovative, culturally suitable service delivery design is needed. WA Cancer & Palliative Care Network, 1 April, 2008, Perth, Western Australia.

**Shahid S**, Pilkington L. Aboriginal perspectives on cancer. Presentation in the BreastScreen WA & WA Cervical Cancer Prevention Programme, Indigenous Women's Reference Groups (IWRG) Meeting, 14-16 November, 2007, Perth, Western Australia.

**Shahid S**, Thompson SC. What does cancer matter?: Aboriginal Australian perspectives on cancer and implications for health service providers. *Mark Liveris Health Sciences Research Student Seminar*, Curtin University, 8 November, 2007, Perth, WA.

**Shahid S**, Thompson SC. Aboriginal Australian perspectives on cancer and its implication in culturally suitable cancer service development. Centre for International Health Conversation Series, Curtin University, 8 October, 2007, Perth, Western Australia.

**Shahid S**. Rural-urban differences in Aboriginal Australian perspectives on cancer. Aboriginal and Torres Strait Islander Health Professional Training, the Breast Cancer Foundation of WA, 24-28 July, 2006, Perth, Western Australia.

**Shahid S**, Thompson SC. Improving cancer-related Outcomes in Indigenous Australians. Presentation at Centre for International Health Colloquium held in July 2 – July 4, 2006.

**Shahid S**, Thompson SC. Rural-urban differences in Aboriginal Australian perspectives on cancer. Presentation at the Office of Aboriginal Health, Department of Health WA, October 2005, Perth, WA.

**Shahid S**. Rural-urban Differences in Aboriginal Australian perspectives on cancer. Presentation at the Centre for International Health Conversation Series on 17 October, 2005.

## Positioning Myself

“How and why did you become involved in this research and where do you come from?” These questions were asked frequently and everywhere I went during data collection and when presenting the research. Yet while I was talking about my background I felt it was connecting me with the people I was yarning (a colloquial term used by Aboriginal<sup>1</sup> people) with, especially with the Aboriginal people involved in the project. Social yarning (Bessarab 2008) as such helped me build relationships and trust with my participants. Therefore I think it is important to outline my place within this research before I proceed further.

I came to Australia in 2005 as an international student to do my Doctorate. Before coming here, I was in Japan with my husband and son undertaking a Masters in International Cooperation Studies which I finished in 2005. I had completed my undergraduate degree in sociology and been involved with health research from its social and cultural perspectives since the start of my research career. My initial thoughts around a PhD topic had centred on exploring sexual behaviour and HIV/AIDS in Bangladesh which I planned to do among married women from different socio-economic backgrounds. I was awarded Curtin International Research Tuition Scholarship (CIRTS) based on my initial research plan, and arrived in Australia to begin research for my higher degree studies.

As part of being oriented to the facilities and processes at Curtin I was told about the funding available to support Higher Degree by Research students, a nominal amount compared to the cost involved for me to undertake fieldwork in Bangladesh. I became concerned at the substantial costs this would involve, with my scholarship the primary means of support for my family at that time. Moreover, that project required me to rebuild the networks I had back in Bangladesh. By the time I came to

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<sup>1</sup> Aboriginal and Torres Strait Islanders are the original inhabitants of Australia, and are often referred to as Indigenous Australians. In this thesis the term Indigenous has been mostly used to refer to First Nation people or the original inhabitants prior to colonisation of different countries, including Australia. The term Aboriginal is preferred by vast majority of Indigenous people of Western Australia, and is used when referring to the study participants.

Australia, I had lost some of my connections, having been living outside Bangladesh for the previous four years. I also thought that it would be difficult to spend a long time away from my family. While they could be in Bangladesh during the data collection phase, it would involve more cost, especially considering the fact that we did not have a source of income in Bangladesh. Thus, I realised that financially and practically, I was not in a good position to pursue my initial ideas for research and I started looking for opportunities to undertake a locally-based research project.

At that time my supervisor received funding from The Cancer Council Western Australia (TCCWA) to provide advice on ways the organisation could contribute more to meeting Aboriginal people's needs for cancer-related information and services in Western Australia. The organisation's interest was catalysed by a small group within TCCWA with an interest in Aboriginal health and the first national cancer forum on cancer issues in Aboriginal and Torres Strait Islander people that had been held in Darwin in 2004. The project was carried out by Centre for International Health in collaboration with the Aboriginal Health Council of Western Australia (AHCWA) and had three components: a comprehensive review of the international and national literatures on Indigenous cancer control issues; an environmental scan to explore what and how Cancer Councils in other states were doing around Indigenous cancer issues and interviews to assess where TCCWA's current cancer-related services for Aboriginal people in WA. I was given primary responsibility for undertaking the literature review for the project, and it was suggested that this could be a fruitful area of research for my PhD.

As soon as I started I realised that cancer was not perceived as a priority health issue for Aboriginal Australians, and it was quite a neglected area. It was clear I would have an opportunity to make an original contribution in this area and it was a promising and important area for research. Moreover, I was based (and employed) part-time at AHCWA while undertaking the literature review in order to immerse myself in an Aboriginal organisation. Participating in the environmental scan and interviews with TCCWA staff provided me with the opportunities to understand issues and the service environment and to begin developing networks within public

health and cancer services in WA. I made the decision in conjunction with my supervisor to pursue this as the area of research for my PhD.

As I read widely about Indigenous cancer issues, it became clear that there was a substantial gap in understanding the socio-cultural issues related to cancer among Aboriginal Australians. This emerged as an exciting area on which to focus my PhD research, and fitted well with my professional training (primarily in Sociology and Social Science Research) and background to date. Nevertheless I was filled with trepidation at the beginning as I knew very little about Indigenous people in this country, and I was warned that undertaking research with Indigenous people was challenging, difficult, time-consuming and demanding. I initially encountered negative comments from some people, particularly Aboriginal people who felt that Indigenous Australians have been over-researched and generally have not benefited from the research done on them.

*I am attending the PHAA conference. There was a workshop session on Indigenous health. There were several Indigenous presentations in that conference. I was just listening to some of the conference presentations, and taking notes, was trying to understand the issues, the context by keeping my mind as open as possible. Some of the presenters were commenting on "using Aboriginal instead of Indigenous", "we want this... we want that". "We have been the most researched population in the world." "Stop doing research." - I am just at the very beginning of my research. I feel like ...oh, my God, how I will survive!!!!... Today it was a shock. I felt that I should read more and more about Aboriginal people and find a way to do more appropriate research. I've become aware of the importance of conducting research that brings benefit to the Aboriginal communities. It is important that people can see the outcome from particular research. (Shahid, From my Reflective Journal, 2005)*

I started reading widely and learning more about Aboriginal people. I read books about the tragic history of how Aboriginal and Torres Strait Islander people had been treated in Australia. A preliminary literature review indicated that there was a lack of research about how Aboriginal people viewed cancer. I was keen to explore the issue of how cancer was viewed in a generic sense rather than restrict myself to a particular type of cancer. By then, I was also well aware of the desire of some health service providers engaged in providing care for Aboriginal people to have a better

understanding of this information and how they could better support Aboriginal people with cancer.

When I read about Aboriginal Australians, I came to know about the distrust they have had towards researchers and towards research overall. This made me very uncomfortable at the beginning but also filled me with a responsibility to ensure my research process was inclusive of Aboriginal people and was undertaken and disseminated in a way that could make a difference. I was constantly aware of my positioning in the research as an outsider, conscious also of the requirement not just to do no harm but also to ensure some good came from this research. This required always reviewing and critiquing my work and approach to the research, and challenging my conventional beliefs, training and positivistic understanding about research.

My conventional scientific perspective about research was constantly confronted. My ultimate aim, at the beginning of my PhD, was to achieve an understanding of human phenomenon and their experiences as objectively and value neutrally as possible. The only sampling strategy I could think of at that time was random sampling strategies and that was the 'ideal type' to me. I thought about representativeness sample size. I planned to do a phenomenological qualitative study but my first draft of 'interview schedule' or 'theme list' was actually a questionnaire! I did not recognise the need for exploring my own epistemological positioning probably because I thought there was only one medium of doing so-called scientific research. As time progressed, I realised that I was coming from a positivistic worldview potentially due to my training in sociology and previous research experience in the area of demography. I recalled some of our methodology classes where quantitative methodology dominated the span of class discussion over qualitative research designs. My PhD research helped me augment my theoretical stance as a researcher. I discovered that I have always been appreciative of the social constructionist worldview but at the same time was surprised to realise that I was totally unaware about this! My choice of methods was not fitting with my philosophical

underpinning. I was ignoring the ‘subjectivity’ aspect of social research on the ground that this is irrational, biased and cannot be generalised.

A bonus to my shift in understanding due to being involved in this area of research was that I was discovering a new paradigm of research – the Indigenous paradigm. I have learnt about a new dimension of looking at research - the power relations between the researcher and the researched population. I have become aware of how we can decolonise the research process and how important the process is for people who participate in research. I became passionate about this critical Indigenous research approach and the contribution social sciences could make within the health services paradigm.

This was how I became involved in this research. It was initially a difficult decision for me to shift my research topic to totally different and unknown territory. But I trusted in my abilities and the integrity I could bring to the research process and kept myself open to new ideas throughout the project. As I developed more long-term relationships with Aboriginal people, I was aware of reciprocity in action and the project became a more collaborative venture. I have learnt much in my own journey including the importance of sharing the struggles, joys and learning from research with the different stakeholders who have helped me overcome all sorts of barriers during my involvement in this project.

One way of documenting some of my learning and experiences was to maintain a reflective journal throughout the project although, honestly speaking, my journaling was quite erratic. I was asked persistently by my supervisor to maintain a detailed, descriptive journal that included insights and reflections on the interview process, the interviews and reflections on the interpretations of participants’ responses. Being a novice qualitative researcher (as my PhD was the beginning of my journey with qualitative research), I could not really foresee the importance and significance journaling back then. I was not quite sure how journals might be written and how they might be used in future. Although I wrote down a lot about my impressions, actions and feelings; I should acknowledge my limitations.

*As my study progresses, I've become more aware of the fact that I did not write down all the right things and with adequate details about my reflections on the whole process of the research and on all the interviews. I think I should have started earlier, and in actual fact, I could have done better in documenting some of my own thoughts and experiences.... I'm not sure whether I was writing too much about my observations while not considering enough about other peoples' circumstances. While I'm looking back, I don't think all of my understanding and interpretations were right about people's responses....*

*But I've learnt through my journey with this qualitative research that this confusion is part of the learning process, and every beginner goes through the same process of uncertainty, confusion and dilemma. As Elly and Associates pointed out, the process of learning to 'do' qualitative research can be very 'messy' but exhilarating.... However, I also found the whole process really exciting, recursive and self-revealing. It has enabled me to become more self-conscious and helped me to reflect back on myself as a researcher. I have learned to criticise myself, to question my positioning as a researcher in a particular context. I have learned that this process of constructive criticism does not actually question or undermine the quality of a researcher rather "enhance the trustworthiness of the research account" (Lincoln and Guba, 1985)....*

*I've now, while analysing and interpreting the data, realised that the reflective diary helps the researcher to discover themselves in a new light where he/she struggles with the complexities and intricacies of field research and his/her own inadequacies. I would have written my reflective journal differently if I started my research now, blending my personal experiences with a bit of touch academic and professional elements. (Shahid, From my Reflective Journal 22.02.2008)*

Despite any reservations, whatever I documented helped me to analyse, understand and interpret participants' responses. I firmly believe that it is imperative to understand Aboriginal decision-making processes and actions against the backdrop of the context and environment that has a significant impact on their lives. I went to quite a remote part of Western Australia for my data collection. I did not have any clue how shocking the experience can be in such an area in a developed country like Australia. Below is an excerpt from my journal while I was in Roebourne.

*Roebourne is a small town in Pilbara. It's near Karratha where the airport is. ... Karratha is a town where most of the shops are located. People from Roebourne go to Karratha for their main shopping. Most of the seriously ill patients go to Perth or Port Hedland for treatment. There is one small hospital in Karratha. If you drive at about 110km/ per hour, it will take about 30 minutes to come to Roebourne from Karratha. There is no Woolies or any other shopping mall for people to buy fresh foods! These remote communities here have very high rates of*



*imprisonment. Policemen, if they see someone on the road at an odd time, rather than asking questions about what's wrong with you or things like that, just take them in to prison. I have come to know that a lot of these are actually because of racism. The major issues of Roebourne are: 'Food insecurity', 'alcohol abuse in one part of the community', 'imprisonment', 'family fights which are sometimes intergenerational', 'drug problems as they grow their own marijuana'. ... We just drove past many places around Roebourne. It's shocking, frustrating to look at how people live in countries like Australia. There are about 20 people living in a small house. I've learned that three generations of people live in one house. Young girls have children at the age of 15 or 16, and by the age of 30 they become grandparents! We visited a few houses. One lady said that she has been living here for 30 years and some houses remain the same for all these years. No development, no renovations... nothing. I was wondering how people from Roebourne would think about cancer? What it means to them? Nothing!!! Or one way of escaping the reality! Especially considering the range of issues they face in their everyday lives!! Discussion about cancer will be pointless to them. I would have just let my life go in that circumstance... not worrying about anything let alone any serious illnesses! (Shahid, From my Reflective Journal, 26.07.2007)*

Although descriptions based on observations as mentioned above were not explicitly used in the final data analysis phase, having them in my consciousness helped me to reveal that part of my horizon that included vulnerability, sympathy, pain and compassion. These aspects certainly influenced the way I interpreted participants' experiences of cancer and my understanding of the research question addressed in this study.

**CHAPTER ONE**  
**Introduction and Overview**

## **1.1 Introduction**

This thesis presents a study of Aboriginal Australians' beliefs and understanding of cancer and their experiences of cancer services in Western Australia (WA). Whilst the diversity of the Aboriginal population of WA needs to be acknowledged at the outset, it is clear that Aboriginal people in Australia generally have worse outcomes from cancer. A much better understanding of why that is so is needed.

The topic of this research arose out of realising that non-Aboriginal health service providers wanted a better understanding of the socio-cultural aspects of cancer in Aboriginal patients, and their sense that they could provide better services and care if they had more information about Aboriginal perceptions of cancer and cancer services.

The study began in July 2005. Ethics approval was obtained from the WA Aboriginal Health Information and Ethics Committee (WAAHIEC) and the Health Research Ethics Committee (HREC) of Curtin University before data collection commenced. After initial difficulties with recruitment and the need to include participants of different genders, educational backgrounds and degrees of acculturation, and my desire to recruit from cancer treatment services, I also obtained ethics approval from two tertiary hospitals (Royal Perth Hospital and Sir Charles Gairdner Hospital). Support was also obtained from the Aboriginal Community Controlled Health Service in Perth (Derbarl Yerrigan Health Service) to enable access to participants through their referrals. The process of talking with a wide range of stakeholders and getting approvals was time-consuming and demanding.

The study was successful in obtaining competitive grant funding for one year from The Cancer Council Western Australia. This covered the costs associated with data collection and visits to remote and rural Western Australia. Information about the aim and objectives of the project and its background were presented widely from the beginning of the research, and there was a high level of interest from diverse audiences regarding the project and its outcomes. Unfortunately two larger funding applications to extend this research and strengthen our capacity-building efforts were

not successful, highlighting one of the struggles to undertake research with Aboriginal people in an optimal way.

This thesis primarily draws on analysis of Aboriginal people's views on cancer and cancer-related services. Interviews were also undertaken with a variety of service providers working in primary and tertiary care in metropolitan, regional and remote areas. The presumption was that this information would complement the views of Aboriginal people affected by cancer but the interviews have to date not been the focus of analysis and writing. This part of the research will gain momentum once this thesis is completed.

The decision to present this thesis as a series of published papers was made in 2008 and was partly driven by the high level of interest in the findings from stakeholders, particularly service providers and planners,. The work has also been widely presented at many meetings and conferences.

## **1.2 Research problem and objectives of the study**

This study was designed to explore the different images (perceptions, beliefs, meanings, ideas, knowledge) and experiences of Aboriginal people in Western Australia (WA) regarding cancer, cancer services and treatment. It also aimed to answer the question of how these images influence Aboriginal people's decision-making processes about accessing cancer-related services and biomedical treatment.

The two main objectives for this research were to:

- identify and explore the variations in understanding, beliefs and views of cancer and cancer services, including treatment, among the Aboriginal population in WA
- explore the diversity in experiences and barriers encountered by Aboriginal people in WA with respect to cancer services and relevant treatment.

### **1.3 An orientation to the thesis**

This thesis is presented in the form of seven published papers, preceded by an introduction and followed by a brief discussion of the findings presented in the papers and their significance. **Chapter 1 - Introduction and Overview** provides an overview of the thesis and the aim and objectives of the research.

**Chapter 2 - Context of the Research**, provides an overview of the study context that includes a description of the geographical diversity of WA and a brief introduction to the history and health of the Aboriginal people of WA. This chapter also briefly covers the health care infrastructure and facilities in WA.

**Chapter 3** comprises the paper titled *Supporting Cancer Control for Indigenous Australians: Initiatives and Challenges for Cancer Councils in Australia*. The paper presents the findings of an environmental scan of current and past programmes and practices in Indigenous cancer control by state and territory member organisations of Australia's peak national non-government cancer control organisation- Cancer Council Australia. The research was conducted in response to a call for Expression of Interest, advertised by The Cancer Council Western Australia (TCCWA) in June 2005, to undertake a research consultancy to assist the organization to improve Aboriginal access and appropriateness of service delivery. A collaborative response was developed by the Centre for International Health, Curtin University and the Aboriginal Health Council of Western Australia (AHCWA). This paper was published in **Australian Health Review**, and identified some of the gaps in initiatives and programmes for Aboriginal people within the Cancer Councils. One of the major recommendations from the staff of the Cancer Councils was the need for research to understand Aboriginal peoples' beliefs, understanding and perspectives on cancer to build capacity among the service providers and to improve Aboriginal cancer outcomes. The environmental scan and the literature review undertaken as part of that research guided the formulation of the aim and objectives of this PhD project.

The second paper, titled *An overview of cancer and beliefs about the disease in Indigenous people of Australia, Canada, New Zealand and the US*, is a published review of the literature for this PhD project. It is included in the **Chapter 4**. This paper was published in **Australian and New Zealand Journal of Public Health**. This literature review provides a brief overview of the epidemiology of Indigenous cancer and explores the similarities and differences in Indigenous understanding and beliefs around cancer in four developed countries: Australia, Canada, New Zealand and the United States. The literature review also identified some gaps in research on cancer among Indigenous populations. This chapter includes an updated version of the literature review undertaken as part of the Cancer Council project.

A detailed description of methods and approaches used in the study is included in **Chapter 5**. A less detailed outline of the methodological details pertaining to this study were published in **BMC Medical Research Methodology**. The title of the paper is *Exploration of the beliefs and experiences of Aboriginal people with cancer in Western Australia: a methodology to acknowledge cultural difference and build understanding*. This paper is also included in **Chapter 5**.

This research project had two major objectives: one was to explore Aboriginal peoples' beliefs and perspectives on cancer in Western Australia and the other was to understand their experiences with cancer and cancer services in WA. In **Chapter 6** the research findings are presented through four published papers. Findings are reported according to various major themes that emerged from the study. In the first paper, titled *Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services*, Aboriginal Australians' beliefs, understanding and perspectives around cancer and how they might impact upon care-seeking behaviour for cancer are described. This paper was published in **BMC Health Services Research**. The other papers are related to the second objective. Aboriginal participants in this study identified some major barriers while accessing cancer services in WA. In the second paper, *Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting*, findings related to communication barriers between Aboriginal people and

health professionals are reported. This paper was published in **Medical Journal of Australia**. The third paper, *“Nowhere to room...nobody told them”*: Aboriginal peoples views on logistical impediments to participation in cancer treatment, has been accepted for publication by **Australian Health Review**. This paper presents another major theme to emerge from the study, described as logistical and infrastructure barriers. The fourth paper, *“If you don’t believe it, it won’t help you”*: Use of bush medicine in treating cancer among Aboriginal people in Western Australia, has highlighted the issue of the importance of traditional healing and bush medicine in the healing process for some Aboriginal Australians and how this might impact upon their decisions about access to mainstream cancer services. This paper has been published by the **Journal of Ethnobiology and Ethnomedicine**.

Each journal article is included in this thesis by publication. The pages in each paper are numbered according to their pagination in the journal and have not been renumbered according to their place within this thesis.

A general discussion of the research findings is presented in **Chapter 6**. The implications from the research are discussed in more detail and more broadly than the discussion sections of the published papers. More attention is given in this chapter to the priorities for future research than could be specified in the limited space of the published papers. Some of the limitations of this research are also reported in this chapter although many of these were highlighted in the published peer-reviewed papers.

**CHAPTER TWO**  
**Context of the Study**



## **2.1 Western Australia: Geography and Population**

Western Australia (WA), the largest state of Australia, covers approximately one-third of the continent(ABC Health and Wellbeing 2007). Despite its size, less than 10% of the nation's total population live in WA. This state has only 2.3 million people, of whom two-thirds live in the metropolitan areas of Perth and Fremantle. The administration of the urban and regional areas of this huge state is divided amongst 142 local government authorities, nine development commissions and a number of state and Australian government departments and organisations(ABS 2002). There were 66 Urban Centres and 108 Localities in WA in 2001 (ABS 2003).

Perth, the capital city of WA, is a large, modern city, often referred to as the world's most isolated capital city. The climate of WA is diverse ranging from a hot and humid north to the moderate south. The central 80% of the state is largely desert with the only significant economic activity being mining. Extraction and processing of a diverse range of mineral and petroleum commodities, agriculture, fishing, and more recently tourism are some of the most important industries of WA. The fertile south west corner is a rich rural and agricultural centre producing most crops and dairy products. The far north east, near the Northern Territory border around Kununurra, was developed over 25 years ago as a vast irrigation area for the production of rice crops and other agricultural products. The North West contains vast mineral wealth as well as considerable oil and gas reserves. Gold is mined at Kalgoorlie in the east of the state and many mining companies have invested in the state (About Australia.com 2010).

## **2.2 Aboriginal people of Western Australia**

Aboriginal people comprise about three percent of the Western Australian population, and in 2006 41% of them lived in remote or very remote areas (determined by distance from urban centres) (ABS 2006). In fact, Aboriginal people of WA are more likely to live in remote areas than Aboriginal Australians in other states and territories. Most isolated Aboriginal communities are in very remote parts of the State (Department of Indigenous Affairs [DIA] 2005). A map in the Appendices shows the diversity of Aboriginal communities in WA.

Between 2001 and 2006, the estimated resident Australian Indigenous population increased by 13%, and WA had the highest growth rate (18%). The vast majority of Indigenous Western Australians stated they are of Aboriginal origin (96%), 1.5% are Torres Strait Islanders, while 2.3% comprised of with dual Aboriginal and Torres Strait Islander origin. In 2006, 34% of the Aboriginal population in WA lived in and closer to Perth, while another third lived in the Kimberley and a third lived in the rest of the state (ABS 2009). Most of the Aboriginal communities are very small in size (ABS 2009). Almost half (48.9%) of the urban centres and localities reported proportions of Aboriginal persons equivalent to, or less than the average of the total Aboriginal people in WA (3.2%). The highest proportions were recorded in the Localities of Bayulu (98.4%), Looma (96.2%) and Bardi (One Arm Point) (95.2%), and in the Urban Centres of Halls Creek (62.6%) and Derby (40.5%) (ABS 2001).

The Kimberley region of northern Western Australia is an enormous area covering more than 400,000 square kilometres, and is home to Aboriginal people of varied language and cultures (Aboriginal Art Online 2000). Aboriginal people in remote regions are inclined to have a greater connectedness with traditional culture, land and ways of life. This may have a protective effect on individual and community wellbeing (Department of Indigenous Affairs [DIA] 2005). However, people living in remote areas deal with huge issues in terms of accessing the basic level of health, education and infrastructure services. Level of access is determined by the level of remoteness of those communities, their size and location. The effects of remoteness are also compounded by the environmental conditions existing in those areas and many of them do not have access to basic essential services such as safe and reliable power, water and sewerage supplies (Department of Indigenous Affairs [DIA] 2005).

### **2.2.1 History of Aboriginal people in Western Australia**

It is vitally important to have a sound knowledge and understanding of Aboriginal history and culture before beginning to work with Aboriginal people. There is a common saying, 'Let's forget the past and get on with the future' (Collard 2000). However, "The past is never fully gone. It is absorbed into the present and the future. It stays to shape what we are and what we do." (Council for Aboriginal

Reconciliation 2000) History is particularly important for understanding the present conditions of Aboriginal people in Australia today. As Collard (2000) states, it is important to remember that “we are the product of our historical experiences, in the same way as we are biologically and socially products of our parents and our upbringing”(Collard 2000) p.22. Thus, it is essential to understand how the culture, history and past policies have shaped today’s Australia and the contemporary experience of Aboriginal people.

Before 1788 Australia was inhabited by Aboriginal people and the island between Australia and Papua New Guinea was inhabited by people now termed Torres Strait Islanders. Together these people are presently known as the Indigenous people of Australia. However, it has only been in the last 30 years that the history of Aboriginal Australia has received any significant interest in the public domain. Although there were many complex and intricate events recorded in oral history, no written documentation of Australia prior to European colonisation existed (Collard 2000). The recording of significant events practised through poetry, lore, songs, music, stories, dance, ceremony and art has not been acknowledged or legitimised by the dominant Australian culture and traditions(Collard 2000).

Conservative estimates suggest that there were between 300,000 and 750,000 Aboriginal people living in Australia prior to colonisation. There were about 500 clan groups each having their unique territory, history, dialect and culture. When the first English settlers arrived in WA in 1829, there were around 60,000 people living in extended family groups across much of the State(Western Australian Centre for Remote and Rural Medicine (WACRRM) 2005). These people were semi-nomadic hunter-gatherers, and had complex kinship systems interwoven into the rich fabric of spiritual and economic life. Aboriginal people’s lives were closely intertwined with nature and the surrounding environment. Despite seasonal fluctuations in the continent, Aboriginal people were provided with a nutritious diet – protein and vegetable foods with adequate vitamins and minerals in every season. As Green (1984) states, Aboriginal people had a kinship with nature and the creatures of the environment. Each society and individual had in-depth knowledge about their lands

and seasons that was communicated through the Dreaming of those societies(Collard 2000). Green (1984) has pointed out all Nyungar, (the inhabitants of the fertile triangle of Western Australia's south-west extending from Geraldton almost to Esperance), for example, traced their origin to the Dreamtime. "Some claimed that their ancestry had been carried to earth on the backs of crows, while others told that their people had sprung from emus" (Green 1984), p.5.

The arrival of European settlers caused a dramatic change to Aboriginal society. This country was colonised on the legal fiction of *terra nullius*, meaning 'a land belonging to no one'. From this time onward, Aboriginal people were not acknowledged or recognised as having rights to their homelands. Unlike other developed nations with Indigenous inhabitants prior to colonisation, Australia never recognised and acknowledged its Indigenous people and way of life by way of a treaty (Collard et al. 2005).

Colonisation has had a devastating impact on physical, spiritual, social and cultural wellbeing of many societies around the world. In Australia, European intervention caused rapid changes in the life of Aboriginal Australians. The people were dispossessed of their land and the transfer of traditional knowledge was disrupted. Aboriginal people were removed from their territory by European guns and laws(Green 1984) p,7. The Aboriginal population was decimated by massacres and diseases. The physical and psychological effects of displacement also contributed to the rapid decline of the population(Collard 2000).

Since the European settlement and until very recently, government policies in this country relating to Aboriginal people have been developed and implemented by mostly non-Aboriginal people. Initial intrusion was followed by policies and practices that aimed to exert full European control over the Indigenous population. The 1905 Act was one of those pieces of legislation. Apparently introduced for the 'better care and protection'(Collard 2000) of the Aboriginals, it served the interests of the colonisers and attempted to control every aspect of Aboriginal people's lives. Institutionalised racism reached its peak in the 1930s. In 1930, the state government

in WA introduced even more oppressive legislation with the 1936 Native Administration Bill. As Haebich (1992) pointed out this Bill ensured the following restrictions:

- People with less than one-fourth of Aboriginal descent were not allowed to live with people who were classified as ‘natives’, even if they were related.
- No Aboriginal person was allowed access to alcohol or was permitted in the grounds of any hotel.
- Any Aboriginal child (under 21) was allowed to be taken away from their parents and placed in an institution to be trained in the ways of ‘White civilisation’.
- All ‘natives’ required permission to marry, to obtain a job, and to travel.

This legislation devastated Aboriginal peoples’ lives. Aboriginal children were removed from their parents. Aboriginal people were not considered to be socially capable of raising their children. During this period, many thousands of Aboriginal children throughout Australia were removed from their families and trained to be maids and domestics(Collard 2000). These experiences created enormous psychological and emotional trauma within Aboriginal communities, and the legacy of distrust is evident in contemporary society. Many parents were unable to stop the authorities while their children were taken away from them; they had been beaten, and some eventually turned to alcohol and other substances to cope with their trauma(Collard 2000; Commonwealth of Australia 1997). This in turn created many health problems and issues that are now a burden to Aboriginal peoples themselves and to the Australian health system. The physical and emotional damage to those taken away was intense and enduring. Most grew up in a hostile atmosphere without family bondings or cultural identity. As adults, many Aboriginal people suffered insecurity, lack of self esteem, feelings of worthlessness, depression, suicide, violence, delinquency, abuse of alcohol and drugs and an inability to trust. Lacking a parental model, many have had difficulty bringing up their own children. The scale of family separation has also had deep consequences for the whole Aboriginal community. Anger, powerlessness and lack of purpose and an enduring distrust of Government, policies, police and government officials developed in them(The

European Network for Indigenous Australian Rights 2007). The major task confronting Aboriginal people throughout this period was how they, their family and their cultures could survive (Collard et al. 2005).

At the time of European settlement there were an estimated 250 distinct Indigenous languages across Australia. More than half of these are no longer used. Many of those remaining are known to only a few elders and face extinction if urgent steps are not being taken to record them. In remote areas of Australia, relative isolation from white influences has resulted in the persistent use of the local languages. Even though the languages are quite different from each other, many Aboriginal speakers can speak more than one language fluently. This proves the interaction that Aboriginal people have between different language groups (Department of Foreign Affairs and Trade 2008).

It is important to recognise the diversity of Aboriginal culture and lifestyle. The process of colonisation, the impacts of assimilation and the removal of people have all impacted upon the already huge diversity of Aboriginal people. This diversity also exists across WA considering the state's geographical diversity (See Map of Aboriginal communities in WA in Appendix 1).

### **2.2.2 Overview of health of Aboriginal people in WA**

Despite difficulties with Aboriginal enumeration and data it is clear that Aboriginal people experience poorer health and die at a much younger age than non-Aboriginal Australians (ABS 2003; Australian Institute of Health and Welfare 2003). In the period 2005-2007, WA had the second lowest figure (65 years for male and 70.4 years for female) for life expectancy at birth for Aboriginal Australians (after NT) (Kennedy and McGill 2009). These figures are approximately 14 years lower than for other Western Australians. For almost all health status indicators, the Aboriginal level is worse than that of non-Aboriginal Australians (Australian Institute of Health and Welfare 2003).

In WA, respiratory, gastrointestinal, infectious and parasitic diseases are disproportionately higher especially among the young Aboriginal people. Geography is a key determinant of health. While deaths due to heart disease, cancer, diabetes, respiratory diseases and injuries remain major issues for all Aboriginal people, Aboriginal people living in rural WA generally experience a greater risk of poor health, higher rates of mortality and hospitalisation than those living in the metropolitan area(WA Country Health Service 2006).

There are many rural and remote factors impacting on these health outcomes. The cost of fresh food is between 150-180% of capital city prices in some remote communities, which has a disproportionately adverse impact given many Aboriginal Australians are unemployed and have limited disposable income. Education, numeracy and literacy levels are significantly lower in Aboriginal compared to non-Aboriginal communities, and access to basic health services is poor, often rudimentary or non-existent, or not accessible to many Aboriginal people residing outside metropolitan and regional areas (Simpson 2009). Major problems are reported in rural WA with water supply and sanitation, overcrowding and substandard housing, waste-water disposal and the absence of rubbish disposal that contributes to a high prevalence of vermin and pests, and a lack of hygiene (Australian Institute of Health and Welfare 2003). There are also problems related to limited employment opportunities and distance from employment (Simpson 2009). Moreover, historically health services in these areas have been culturally inappropriate due to cultural and geographical inaccessibility, and cost factors.

Other factors include substance abuse, poor nutrition, obesity and exposure to violence. Furthermore, morbidity data point out that many Aboriginal people are unwilling to seek medical attention until their condition is serious (Simpson 2009). High levels of Aboriginal physical and mental illness and poor access to health services result in many Aboriginal people suffering preventable chronic diseases that could have been better managed through early identification and treatment.

### **2.3 Health Care Infrastructure in WA**

The major public teaching hospitals in WA are all based in Perth. They are: Royal Perth Hospital, Sir Charles Gairdner Hospital, Fremantle Hospital, King Edward Memorial Hospital for Women, and Princess Margaret Hospital for Children. They provide a broad range of specialty services, for example, intensive care, vascular, cardiothoracic, oncology, renal, neurosurgery and obstetrics (ABC Health and Wellbeing 2007).

There are nine major regional public hospitals at: Albany, Narrogin, Bunbury, Northam, Kalgoorlie, Geraldton, Carnarvon, Port Hedland and Derby; and 68 smaller hospitals located in country areas. These hospitals provide a wide range of services that include emergency, medical, surgical, paediatric, obstetric and rehabilitation services. WA also has 36 private hospitals throughout the state (ABC Health and Wellbeing 2007).

In metropolitan and larger country centres, a wide range of services are provided by government-funded health centres and nursing posts, including private organisations (which often receive government support). Their services range from women's health, counselling, drug and alcohol, to family planning services. Many church and charitable organisations provide services such as aged care (ABC Health and Wellbeing 2007). In some areas, health services are delivered by Multi Purpose Services – combined hospital and nursing posts which are customised to meet local needs (ABC Health and Wellbeing 2007).

Health care in remote regions of Western Australia is delivered by government salaried GPs or District Medical Officers (DMOs) from the regional hospitals who travel to remote communities. Salaried GPs working in remote areas are less common. They work in a team with Remote Area Nurses (RANs) who work from government-funded Remote Area Nursing Posts, and Aboriginal Health Workers (AHWs). In many areas Aboriginal Community Controlled Health Services (ACCHS) provide clinical, prevention and support services provided by GPs, nurses, AHW and other health professionals. In some cases AHWs work with nangkaris



(Aboriginal traditional healers). An ACCHS (also known as an Aboriginal Medical Service or AMS) is a primary health care service initiated and operated by the local Aboriginal community to deliver holistic, comprehensive, and culturally appropriate health care to the community. A locally elected Board of Management provide overall governance of the ACCHS or AMSs (National Aboriginal Community Controlled Health Organisation 2008).

Almost half (42.7%) of the general practitioners currently working in rural and remote WA received their primary medical qualification abroad. Of these, 29% are from the UK, 20% from South Africa, 7% each from Netherlands and India and 6% from Nigeria. Other countries represented include: Ireland, Pakistan, Singapore, New Zealand, Germany, Egypt, Burma, Poland, Sri Lanka, Canada and many more (Western Australian Centre for Remote and Rural Medicine (WACRRM) 2005). The workforce in the public hospital and community health sector is dominated overwhelmingly by non-Aboriginal people even in regions where a significant proportion of the client base is Aboriginal (Department of Health 2008).

Specialist treatment usually involves transport of patients to larger centres (usually Perth, or Darwin for patients in the far north). Transport of patients to central areas, and of health workers to remote areas, is often delivered by the Royal Flying Doctor Service(ABC Health and Wellbeing 2007).

Transportation and infrastructure generally depends on the size of the community. A state, territory or local government authority is responsible for maintaining roads and aerodromes only in major communities which have at least 200 people and these communities are usually accessed by a highway. In minor communities (fewer than 200 people), outstation resource agencies or community councils are responsible for maintaining roads, airstrips and freight boats. However, these organisations often lack the specialist capacity and funds for this work (ABS 2006).

In many circumstances, general health services do not efficiently meet the particular needs of Aboriginal people. It has been demonstrated that health services for Aboriginal people are more effective if they are delivered by people with an affirmative approach and understanding of Aboriginal culture and lifestyles(Simpson 2009). Increasing the number of Aboriginal employees at all levels throughout the health system will contribute to culturally 'secure' health services. The establishment of ACCHS promotes the responsibility and understanding that Aboriginal people need in order to have self-determination in health delivery.

The State Government of WA has expressed strong commitment to the health of Aboriginal people and supports that interest with a wide range of services(Department of Health 2010). In theory, State-funded hospitals and health services need to give special attention to the needs of Aboriginal people and ensure services are provided in a culturally appropriate manner. However, the ongoing poor status of Aboriginal health shows that more effort is needed to find better ways of working with Aboriginal communities, General Practitioners (GPs), hospitals and non-government organisations (Department of Health 2010).

The State Government also funds various high priority projects that are aimed at improving the health of Aboriginal families, including nutrition and substance abuse programmes, disease prevention, and environmental health in Aboriginal communities. In addition to the wide range of health care services provided by government, further support is provided by a growing network of ACCHS and other community organisations. A network of public, private and non-government services provide community health services to help people with most common health problems. Their services include: health promotion and education; family health care including screening, immunisation and treatment of infants and school-aged children; health care to those who may have special needs such as Aboriginal people, women, people with severe disability or disease, older people, low income earners and people in remote areas; nursing and therapy services; palliative care; and multicultural services (Department of Health 2010).

In accordance with the philosophy of self-determination, Aboriginal communities run over 140 ACCHS across Australia. Some of them are quite large multi-functional services that employ several medical practitioners and provide a wide range of services. However, some of them are small services without medical practitioners and they rely on mainly Aboriginal health workers and/or nurses to provide the bulk of primary care services, often with a preventive, health education focus(National Aboriginal and Torres Strait Islander Health Clearinghouse 2000). The services form a network, but each is self-directed and independent both of one another and of government. The integrated primary health care model of ACCHS was developed based on the philosophy of Aboriginal community control and the holistic view of health (National Aboriginal and Torres Strait Islander Health Clearinghouse 2000).

The National Aboriginal Community Controlled Health Organisation (NACCHO) is the peak body for ACCHS and represents local Aboriginal community control at a national level to ensure that Aboriginal people have greater access to effective health care across Australia. NACCHO provides a coordinated holistic response from the community sector, advocating for culturally respectful and needs-based approaches to improving health and well being outcomes through ACCHS(Human Rights and Equal Opportunity Commission 2008; National Aboriginal Community Controlled Health Organisation 2008). The Aboriginal Health Council of Western Australia (AHCWA) is the peak body for 19 Aboriginal Community Controlled Health Services (ACCHS) in WA. AHCWA develops and provides constructive educational health courses and programmes and undertakes medical research to redress ill-health within the Aboriginal community. The organisation delivers holistic and culturally appropriate health and health related services to the Aboriginal community (Department of Health 2007).

**CHAPTER THREE**  
**Setting the Scene**

To Whom It May Concern

I, Kerri R Beckmann, was involved in the initial designing of the project with the Cancer Council Western Australia. I also undertook some of the interviews as part of that project.

I was also involved in the writing of the paper published as:

**Shahid S, Beckmann KR, Thompson SC. Supporting cancer control for Indigenous Australians: initiatives and challenges for cancer councils. Australian Health Review 2008; 32(1):56-65.**

The writing of this paper was led by Shaouli Shahid. I commented upon the initial draft, checked and approved the final version of the article.



(Signature of Co-Author)

Kerri R Beckmann



(Signature of Candidate)

Shaouli Shahid

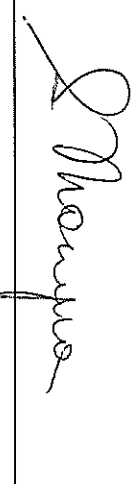
To Whom It May Concern

I, Professor Sandra Thompson, was involved in the project with The Cancer Council Western Australia.

I coordinated the whole project, participated in the design and assisted with the conduct of the study. I was also involved in the writing of the paper published as:

**Shahid S, Beckmann KR, Thompson SC. Supporting cancer control for Indigenous Australians: initiatives and challenges for cancer councils. Australian Health Review 2008; 32(1):56-65.**

The writing of this paper was led by Shaouli Shahid. I commented upon the initial draft, checked and approved the final version of the article.



(Signature of Co-Author)

Sandra C Thompson



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## Supporting cancer control for Indigenous Australians: initiatives and challenges for cancer councils

Shaouli Shahid, Kerri R Beckmann and Sandra C Thompson

### Abstract

As in other developed countries, the Australian population is ageing, and cancer rates increase with age. Despite their substantially lower life expectancy, Indigenous Australians are also experiencing concerning cancer statistics, characterised by increasing rates, later diagnosis, higher mortality, and lower participation in screening than the non-Indigenous population. Eighteen months after the first national Indigenous Cancer Control Forum, this environmental scan within the state-based Cancer Councils was undertaken to map activities in service provision in Indigenous cancer control with a view to sharing the lessons learned. The findings show that although most of the organisations had tried to work with Indigenous communities on cancer issues, there have been difficulties in building and sustaining relationships with Indigenous organisations. Lack of having Indigenous staff internally, few Indigenous-specific resources, and few planned, long-term commitments were some of the major impediments. Some of these limitations can easily be overcome by building and improving regional or local partnerships, providing cultural awareness training to internal staff, and by building the capacity of Indigenous organisations. Health promotion projects of the Cancer Councils directed at Indigenous people could be more effectively implemented with such considerations.

Aust Health Rev 2008: 32(1): 56-65

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### What is known about the topic?

For many years cancer was not considered a high priority issue for Indigenous Australians as a consequence of social and other health issues. Cancer incidence and death rates of Indigenous Australians have been unclear as there has been limited epidemiological information and misclassification of Indigenous status. It is now evident that the pattern of cancer differs for Indigenous Australians, and Indigenous people tend to be diagnosed later, have poorer participation in treatment and a higher mortality rate for any equivalent stage of diagnosis.

### What does this paper add?

This paper presents a snapshot of the staffing, projects, programs and activities of the state Cancer Councils in early 2006 in terms of efforts to progress cancer control issues focussing on Indigenous Australians. Most successful initiatives began by establishing a relationship and working over the longer term to sustain program activity.

### What are the implications for practitioners?

Insights from the analysis of progress in the cancer field are relevant and applicable to practitioners in other areas of health where mainstream services have a role to improve the health of Indigenous communities.

THE NUMBER OF recorded cancer deaths in Australia continues to increase, attributed in part to the increase in cancer incidence that occurs in an ageing and an expanding population.<sup>1,2</sup> Until recently, cancer was seldom identified as a priority health issue for Aboriginal and Torres Strait Islander (hereafter Indigenous) Australians.<sup>3</sup> The immediate health and welfare problems of Indigenous Australians across the lifecycle are well documented,<sup>4-6</sup> and these may have distracted attention from the fact that cancer has

<sup>1</sup> Australia has two groups of Indigenous populations: Aboriginal, and Torres Strait Islanders. In this paper, we will use the term "Indigenous" to refer to both Aboriginal and Torres Strait Islander peoples.

become one of the major causes of death for these people. Interest about cancer among Indigenous populations may also be affected by their lower incidence of many cancers and their shorter life expectancy. Moreover, cancer rates in Indigenous Australians may under-represent the real burden because of misclassification and under-ascertainment of Indigenous status.<sup>7-9</sup>

Nevertheless, available data show that Indigenous Australians are experiencing an increasing rate for some cancers.<sup>3</sup> For almost all cancers, they experience later diagnosis, lower 5-year survival and a higher mortality rate than non-Indigenous Australians.<sup>10</sup> Indigenous women have lower participation in mammography and Pap smear screening than non-Indigenous women.<sup>11,12</sup> It has also been reported that the overall response rate was significantly lower for Indigenous people than the general population in the Bowel Cancer Screening Pilot Program that ran between November 2002 and June 2004 at three sites in Australia.<sup>13</sup> Moreover, while the last two decades have seen a 30% reduction in cancer mortality rates in Australia, there has been little impact upon Indigenous cancer mortality.<sup>14</sup> The need to prioritise cancer prevention and control was recognised in the National Indigenous and Torres Strait Islander Health Strategy 2001, where cancer was documented as one of three major chronic diseases for Indigenous Australians.<sup>15</sup>

The first national forum to discuss Indigenous cancer issues, held in Darwin in August 2004, highlighted various gaps that exist around responding appropriately to these issues. Many strategies were proposed to improve their poorer cancer outcomes. Increased government funding, boosting research on cancer among Indigenous Australians by enhancing their ownership over the data, and involving them in partnership with non-Indigenous health professionals to ensure appropriate service design and delivery mechanisms were a few of the significant recommendations. At the conclusion of the forum, the peak non-government organisations providing advocacy for prevention and care for cancer in Australia, The Cancer Council Australia and its state-based affiliates, committed to factoring Indige-

nous issues into their policy development and advocacy for cancer prevention and care.<sup>14</sup>

This paper summarises the findings of an environmental scan of current and past programs and practice in Indigenous cancer control by state and territory member organisations of The Cancer Council Australia. It was primarily undertaken to inform the deliberations of The Cancer Council Western Australia (TCCWA) on its potential role and contribution in improving cancer-related services for Indigenous people in WA. Environmental scanning is a method most commonly used in business but is quite popular in the health care sector around the world,<sup>16-18</sup> and is used to identify emerging issues within the broader economic and political environment.<sup>19</sup> It is similar to situation analysis in which a review is undertaken of health strategies and policies, institutional support systems, programs and interventions with the aim of strengthening health reform and health systems. It differs from audits which generally evaluate performance and are aimed at ascertaining the validity and reliability of information as part of quality control processes. Morrison argues that environmental scanning is a method that enables decision makers both to understand the external environment and the interconnections of its various sectors and to translate this understanding into an institution's planning and decision-making processes.<sup>20</sup> The advantage of environmental scanning for organisational leaders is that knowing both the internal and external environment in which the organisation operates is helpful in planning their future course of action.<sup>21</sup>

The scan was undertaken to identify various Indigenous-specific programs and experiences of the Cancer Councils of Australia 12-15 months following the Darwin forum. This paper highlights the key issues, learning, successes and limitations of related initiatives that have been undertaken by the state Cancer Councils.

## Methods

Environmental scanning was agreed to be a suitable method for learning about how a range of organisations across the sector had approached



**Summary of progress in organisational and program initiatives for indigenous cancer control by participating jurisdictional Cancer Councils, March 2006**

	Jurisdiction						
	ACT	NSW	Qld	SA	Tas	Vic	WA
<b>Organisational</b>							
Indigenous person employed	No	Not current	No	No	No	Yes	No
Position with specific Indigenous focus	No	No	No	Yes (0.2 FTE)*	No	Yes	No
Cultural awareness training	No	Yes	Yes	No	No	Voluntary	No
Specific Indigenous action plan	No	No	Recent	No	No	Tobacco, Cervical screening	No
Indigenous person on board	No	No	No	No	No	No	No
Indigenous representation on working parties	No	Yes	No	No	No	Yes	No
Links with ACCHOs	Strong	Beginning	No	Yes	No	Yes	Ad hoc
<b>Specific programs</b>							
Cancer awareness/health promotion at Indigenous events	Yes	Yes	Yes	Yes	No	Yes	Yes
Tobacco control	Sustained	Yes	Yes	Yes		Sustained	Yes
Cervical screening			Limited	Yes		Funds VAHS +	
Breast cancer awareness			Ad hoc				Ad hoc
Aboriginal health worker training		Yes	Yes			Yes	
Cancer support and care			Yes	For women			
Speakers	No		Yes				No
Indigenous-focussed resources	Limited	Limited	Yes	Limited	Limited	Yes	Beginning
Data on Indigenous cancer statistics	No	Yes	Beginning	Yes	No	Yes	Yes

\* A non-Indigenous person spends 1 day a week on Indigenous cancer issue. ACCHOs = Aboriginal controlled community health organisations.

supporting Indigenous cancer control approaches and gathering information about successful initiatives and efforts that had been less productive, and this approach was accepted by a Steering Committee and approved by the Curtin Health Research Ethics Committee.

An initial approach letter was mailed to the Chief Executive Officers/Directors (CEOs) of all the Cancer Councils, outlining the background to the survey. They were also requested to nominate appropriate staff members who could be interviewed about their organisations' past or present

initiatives to improve Indigenous engagement with cancer issues and to pass the background information about the study on to those they nominated. When the individuals were contacted and nominated others, these additional nominees were also interviewed if available and willing. A copy of the letter sent to their CEO was provided to the participants beforehand.

Semi-structured interviews, either face-to-face or by telephone, were undertaken with the key nominated staff (Indigenous and non-Indigenous). The interview was based upon a theme list

developed following a review of relevant literature and discussion within the research team. The list was also discussed with Indigenous colleagues and forwarded to a Steering Committee established to oversee the project of which this scan was a component. Key areas focusing on Indigenous Australians that were considered during the interviews, included: cancer prevention and education; cancer support services for Indigenous health organisations; health care delivery (workforce/access to health care services); research; advocacy/policy and human resources and any cross-organisational initiatives. Interviews were taped with the permission of participants, and the responses were coded following the key themes of the interview schedule. Thematic analysis was undertaken manually, in which the efforts and experiences of each Cancer Council were recorded against the major service areas.

Staff from The Cancer Councils of the Australian Capital Territory, Tasmania, Victoria, New South Wales and the Cancer Foundation of Queensland participated in telephone interviews. Information was collected from staff at the Cancer Councils of Western Australia and South Australia through face-to-face interviews. Before submission of this article for publication, it was circulated to the CEOs of all participating Cancer Councils, giving them the opportunity to make additions or corrections, and appropriately represent their organisation, and suggested amendments were incorporated.

### **Findings from the scan**

Most interviewees indicated that their organisation had tried to work with Indigenous communities on cancer-related issues. Working in partnership with Indigenous organisations was seen as important, and perhaps more effective than establishing Indigenous-specific positions within the organisation. However, a number of respondents noted the difficulty of building and sustaining relationships with Indigenous health agencies because they were under-resourced to respond and cancer is not prioritised among many competing social and health issues. Key

findings related to Indigenous cancer control are summarised in the Box. Further details are reported according to core functional areas.

### **Education and training**

Capacity building within the Indigenous health sector was identified as a priority area, in which respondents believed Cancer Councils could play an important supportive and advocacy role. Some success was reported in running training programs with Aboriginal Health Workers (AHWs). The most promising example was initiated by The Queensland Cancer Fund (QCF). Based upon the priorities identified through consulting Indigenous groups and other key stakeholders, a cancer care course was developed for AHWs with assistance from an Indigenous advisory panel in developing the course content. The five-day program introduced various aspects of cancer treatment and care, and provided site visits to various cancer support services. Overall, it was felt the course provided a good overview for the AHWs on the rationale and practical aspects of cancer treatment and insight into what patients go through during treatment. Scholarships were provided to 14 health workers from across Queensland to attend the first course, and this helped with the development of networks between AHWs and cancer service providers. Indigenous participants were generally identified through the regional officers of the QCF and contact with Indigenous communities. The desirability of one-to-one follow-up and support after training, utilising regional officers, was emphasised. The QCF has also trialled a less intensive version of education, for example, by adapting a mainstream 2-day training program for community speakers around prevention and awareness of cancer for delivery to AHWs in northern Queensland. A small number of volunteer Indigenous speakers were trained through this program to increase cancer awareness in their local communities.

Cancer Councils in some other jurisdictions have also tried to arrange training programs with AHWs, although some reported receiving a low level of interest from the stakeholders. TCCWA regularly contributes to teaching around cancer

within metropolitan-based AHW training. Others, in partnership with Indigenous Community Controlled Health Organisations in their areas, have begun planning to incorporate cancer awareness into AHW training, but not all discussions have yet resulted in established commitment. The Cancer Council Victoria (TCCV) has, since 2001, been delivering training on cancer, screening and cervical cancer to AHWs undertaking the Certificate 4 in Women's and Babies' health which is delivered by the Victorian Aboriginal Community Controlled Health Organisation.

The Cancer Council New South Wales (TCCNSW) had organised one-day training workshops for AHWs covering basic information about cancer biology, prevention, early detection, treatment and end of life which were jointly delivered by two Aboriginal consultants. However, the workshops have not been systematically and regularly conducted. The organisation now proposed to develop a more sustainable, organised program with regional Aboriginal Health Services (AHSs) interested in this approach. Implementation may occur by extending the 1-day training workshop to 2 days, and shifting the focus to include more practical issues related to cancer care.

Lack of availability of Indigenous-specific resources was mentioned as a barrier to education about cancer. TCCV has supported development of many Indigenous-friendly resources addressing smoking cessation and cervical screening. Respondents were also aware of resources in the process of development by other organisations such as The Centre for Excellence in Indigenous Tobacco Control, and felt that specific resources would be helpful in address Indigenous needs. It was considered important to develop educational and outreach materials that included artwork, pictures, role models and/or stories resonating culturally with the program's target population. It was also stressed that any resources produced must be appropriately used, because in some instances, good resources remain under-utilised as a result of inadequate promotion, poor distribution or inadequate staff training in their appropriate use. Although there was recognition that resources designed in another jurisdiction were

not always suitable and relevant elsewhere, some respondents noted a lack of capacity within their organisations in adapting these or developing new resources.

### **Education of cancer staff about Indigenous people**

Training and capacity building are not only necessary for AHWs and community members. Respondents acknowledged the need for awareness of Indigenous culture, cultural differences and beliefs to be taught and understood among the mainstream health service providers. The QCF runs cultural awareness training for staff twice a year, with training provided by the Department of Health and delivered by an Indigenous person. The TCCNSW has been running 2-day workshops on Indigenous culture for about 5 years, and it is mandatory for all staff. TCCV have organised cultural awareness training in 2001 and 2005, and they now plan to deliver it annually.

### **Cancer prevention education**

The focus within cancer prevention was strongest in the area of tobacco control, and primarily focussed on education and support initiatives. For instance, TCCWA provides support and advice to Say No To Smokes, the only Aboriginal-targeted tobacco control project in WA. Working in collaboration with the Say No To Smokes team, the partners have now submitted a joint funding proposal for another project, the brainchild of an Aboriginal ex-smoker, to capture and tell in their own words the success stories of Indigenous people who have stopped smoking. The Australian Capital Territory Cancer Council in partnership with Winnunga Nimmijah runs a smoking cessation program No More Bunda for Indigenous people that includes access to free nicotine-replacement therapy (NRT). This program was adapted from a standard cessation program and has been running for 5 years. TCCV is working in two program areas — tobacco control and cervical screening — to take on an Indigenous-specific focus, and to train and support AHWs. TCCSA supports and plays partnership roles with the

Aboriginal Health Council of South Australia to deliver a Quit Skills training program to AHWs. TCCNSW appointed an Indigenous representative on the planning committee for a tobacco control conference and provided 12 scholarships for Indigenous people to attend.

In reporting on successful initiatives, respondents often described relatively small-scale local or regional initiatives where the kernel of the project came out of a personal or good relationship between a Cancer Council member and an Indigenous person working in a local health service or in the community. Such partnerships recognised that Indigenous Health Services are experienced in working with Indigenous people, while the Cancer Councils have expertise around cancer education and supporting people affected by cancer. Building relationships and reciprocity through sharing information and skills between organisations was valued by the informants. A local or regional approach was seen as better able to support the diverse needs of the Indigenous population within each state.

### **Indigenous employment**

Involvement of Indigenous people was acknowledged as a crucial factor in every aspect of cancer-related service delivery. However, only one of the Cancer Councils (TCCV) during the project period reported having an Indigenous staff member. While some Cancer Councils had experience in recruiting Indigenous staff, respondents recognised the inherent problems of appointing one Indigenous person to provide advice across the organisation. Based upon their observations and experience, respondents believed that it was difficult to recruit Indigenous staff with the skills and knowledge to hit the ground running. One respondent proposed the merits of two or three part-time positions working together on one project instead of one person across the whole organisation.

Respondents were aware of the need to provide orientation, adequate direction and support to Indigenous staff in the same way as other staff members, but some noted that there had been difficulties in achieving this in practice. There

were risks of Indigenous staff members feeling isolated, and either not performing to their ability or suffering burnout. Some respondents proposed the need to encourage Indigenous employees to network with other Indigenous people in the health sector if there were not other Indigenous employees within the organisation. In the absence of Indigenous staff members, some organisations are working with Indigenous volunteers and some with non-Indigenous staff, generally through linking with Indigenous health service organisations.

### **Policy and advocacy**

The need for Indigenous people to be involved in setting the agenda and deciding priorities was consistently recognised by the respondents — as it is in the literature. But respondents also acknowledged that initiatives would have to fit within the Cancer Councils' scope and priorities. Cancer Council staffs are aware of their reliance upon donors and fundraising events, and were cautious about undertaking activities that might offend donors or distract from their mainstream business. A number of the informants described their organisation as "white middle class", not intended as criticism but rather as a statement of where they were in their historical development. In some jurisdictions, programs for culturally and linguistically diverse populations were also acknowledged as relatively under-developed. The Cancer Councils generally had not adopted specific Indigenous action plans, although they had strategic plans that addressed social determinants of health inequalities, special needs groups and under-served populations.

Informants generally felt that insufficient time and effort had been put into Indigenous cancer issues within their organisations to date. What had been undertaken was described by some as piecemeal, "just scratching the surface". There were some criticisms that efforts had not generally been sustained over time. For example, one respondent reported that their organisation had been running programs like a 1-day workshop on Quit skills to raise awareness; promoting discussion about priorities and areas for action to

support Indigenous cancer support group; running projects with young Indigenous women smokers to quit smoking and so on. However, systematic efforts with follow through have only recently begun, and are still at an early stage of development. Some Cancer Councils have established a staff Aboriginal Health Interest Group. At TCCV a voluntary group with representatives from most Units was established in 2002 and meets quarterly to discuss Indigenous issues, provide cultural awareness opportunities and links with external Aboriginal health agencies. The group enables increased awareness of Indigenous needs and information goes back to Units to address.

#### **Cancer support services**

Cancer support services provide support across a range of needs to people during their cancer journey, from counselling newly diagnosed cancer patients, their families and friends, to providing emotional and practical support, advice, accommodation and assistance with palliative care. None of the Cancer Councils reported that Indigenous people were truly represented in their client groups. However, TCCSA had supported the establishment of an independent Indigenous Women's Cancer Action Group that provides support to other women with cancer.

Underlying issues for inclusion of Indigenous people in cancer care and support emerged during the interviews. With regard to accommodation facilities, some informants reported there had been tensions related to large families visiting and staying, mess, dirtiness and noise. It was widely reported that many staff felt ill equipped to deal with the cultural differences of Indigenous patients, and some staff were uncomfortable in dealing with Indigenous families. They did not understand the values and customs of Indigenous people, while language difficulties further impeded communication. Often there was no access to interpreters when the person spoke an Aboriginal language as their first and usual language. There were also issues with some Indigenous clients not wanting to be alone in private rooms, preferring being at floor level rather than

bed height, having different dietary preferences and their preferred foods being unavailable. Despite challenges in communication, staff often understood the desire of rural patients to return home to die, but it generally had required dedicated effort and substantial cost to achieve this.

A number of informants spoke of the importance of improving the quality of data around Indigenous cancer and needs. Good information serves as the impetus for setting priorities and directing resources, giving individuals a rationale for further work with a minority population. Baseline data for monitoring progress was seen as vital for people in the field.

#### **Discussion**

Cancer Councils in Australia have been highly effective non-government organisations with considerable expertise on all aspects of cancer control. As a result of their strategic approach, they are effective advocates around cancer screening, treatment and support services. As key players in cancer control, they contribute through education, training, research, advocacy and cancer support service functions, all of which are necessary components of achieving improved cancer-related outcomes for Indigenous Australians.

Cancer Council staff acknowledged the limitations of their organisations in addressing Indigenous cancer issues and their own deficiencies in understanding Indigenous culture and hence the "right" way to do things. But their willingness and enthusiasm to work with these communities was apparent in the organisation and participation at the 2004 Indigenous Cancer Control Forum in Darwin, and this was followed by new initiatives within many of the Cancer Councils. These initiatives include planning for a state-based Indigenous Cancer Forum in South Australia (held in September 2006), training of AHWs, cultural safety training for non-Indigenous cancer support staff, and working in collaboration with local and regional Indigenous health organisations.

Limitations identified in the environmental scan which impeded progress on Indigenous cancer issues were the lack of dedicated staff time

for Indigenous issues, lack of Indigenous staff, limited commitment of significant resources on a sustained basis, and lack of Indigenous input into policy and programs. There were no Indigenous Board members, and where an Indigenous person had been appointed as a staff member, often many demands were made upon them. Some were uncomfortable working in a mainstream organisation without Indigenous colleagues providing peer-support. While it was recognised as desirable to have Indigenous staff members working within the organisations, respondents appreciated the practical challenges of this, and that an Indigenous person *per se* was not a panacea. Most organisations therefore opted to develop linkages with Indigenous health organisations, and in some instances such projects had been sustained over a number of years, with resources committed over that time period. The linkage approach sometimes proved frustrating as it often relied upon individual relationships and required that the Indigenous organisation have both capacity and commitment to the partnership.

Informants recognised the necessity to build capacity around cancer within the Indigenous health sector. Considerable activity, not all of which had yet come to fruition, had been initiated at planning and service levels subsequent to the Darwin forum, and the project funded by TCCWA, of which this scan is a component, exemplifies the interest in how Indigenous cancer control might be progressed. An intensive week of training with ongoing opportunities for networking and relevant professional development seems a particularly useful approach to increasing Indigenous capacity around cancer issues.

Activities and projects catalysed by small seed project funding and initiated regionally or locally within established networks, were often cited as successes. However, such successes had not generally been translated into sustained activity or programs. Participants consistently recognised the importance of long-term and well planned programs with dedicated resources.

Practitioners involved in health promotion with Indigenous clients advocated the use of "non-preachy" methods, that is, approaches that appeal

to an individual's concern for the health and wellbeing of their family and the community rather than harms to their own health. Thus, messages around tobacco control might focus initially upon harm reduction by preventing passive exposure of family members to tobacco smoke.

Cancer Councils provide support services for people with cancer that recognise the social, spiritual, emotional, and physical supports of cancer patients and their family members. However, most were aware of their own organisational limitations in understanding and capacity, particularly around Indigenous culture and values. Although there has been very limited exploration in Australia of what cancer means to Indigenous Australians, those interviewed recognised that Western psychosocial and support models might not be appropriate for Indigenous clients. This deficit in understanding made service providers feel that they lacked the knowledge and confidence in supporting Indigenous clients well. Staffs were keen to better appreciate Indigenous people's socio-cultural understanding of cancer and to use this knowledge in their practice in cancer service delivery. Many would welcome Indigenous cultural awareness training but wanted specific information around cancer beliefs, not just information about the historical context of Indigenous health.

Although Cancer Councils have a well developed network of volunteers to help support people with cancer, training of existing staff and volunteers to support Indigenous people is needed. It may be helpful to provide Indigenous mentors for non-Indigenous staff who are inexperienced in working with Indigenous people. Recruitment and support for Indigenous volunteers and cancer survivors to assist in cancer advocacy work is in place in SA and Queensland, but not in other jurisdictions. One-to-one support services appear to be underutilised currently, and Indigenous-specific cancer survivor support resources using testimonials or story-telling may be helpful. An issue regularly raised within Indigenous cancer contexts was the use of traditional healers and traditional medicines,<sup>22</sup> although

these issues were generally not mentioned by the informants interviewed. Support programs that integrate cultural components (traditional medicine, selected ceremonies) may be acceptable and effective means of supporting Indigenous people to engage in cancer treatment.

There are many similarities between the cancer issues experienced by Indigenous Australians and those of indigenous people in other developed countries. It is beyond the scope of this paper to discuss in detail the experience in cancer control and support strategies in indigenous populations in countries such as Canada, New Zealand and the United States. However, the authors have undertaken a comprehensive literature review of these populations and key lessons from international experience are: acknowledgement of past treatment and the impact of colonisation; acknowledgement of the cultural diversity of Aboriginal people; recognition of the impact of the structural causes of inequality; need to enable Indigenous ownership, participation, partnership and control, with Indigenous representation at all levels of decision making; and support for community-based and community-driven interventions. There have also been efforts to develop culturally appropriate resources and service-based programs, promoting Indigenous healing approaches concurrently with Western medical treatment. The reader is recommended to read further about these approaches<sup>23-28</sup> which were generally Indigenous community-led and government supported.

While there has been a lack of Australian government leadership in this area, Cancer Councils can play both an effective practical and advocacy role at the local, state and national level to ensure Indigenous issues in cancer control are more effectively incorporated and heeded. Respondents recognised that this should be done "hand-in-hand in partnership with Indigenous communities", and leadership is needed from The Cancer Council Australia to ensure that there is steady national progress with lessons shared across jurisdictions. The need for Cancer Councils to adopt a respectful approach that invests in learning and understanding about Indigenous

issues, and the reciprocal benefits that might derive from such partnerships in enhancing Indigenous cancer control are recognised in the words of one informant:

The Darwin Forum was like ... the Cancer Council people trying to learn from Aboriginal people ... and if we maintain that theme all the way through our state-based work or national work, we will do ok ... because we have developed lots of respect in taking that approach ...

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### Competing interests

The authors declare that they have no competing interests.

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**CHAPTER FOUR**  
**Literature Review**

## 4.1 Cancer and its impact

Cancer has become a major component of the total burden of disease worldwide, especially in developed countries. The twentieth century recorded the greatest advance in the control of human disease (Freireich 2001). While many infectious diseases were controlled, because of the ageing of the population and a strong association between cancer and age, cancer was becoming more prevalent and now represents a major health issue of the twenty-first century. Until 1960, no one had claimed that a systemic or metastatic form of cancer could be cured. In only 35-40 years, techniques for the early detection, prevention, surgical and radiation therapy treatments improved markedly and at least 15-20% of patients with systemic/metastatic cancers can now be cured (Freireich 2001; Ma and Yu\* 2006). Recent Australian survival data shows that approximately 60% of people diagnosed with cancer are still alive after five years (Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR) 2001).

Cancer is a term used for a group of several hundred diseases in which abnormal cells are not destroyed by normal metabolic processes but instead divide without control and are able to invade other tissues (AIHW (Australian Institute of Health and Welfare) and AACR (Australasian Association of Cancer Registries) 2008). Cancer cells can spread to other parts of the body through the blood and lymph systems. There are more than 100 different types of cancer (National Cancer Institute 2009). For most cancers the causes are not fully known but research shows that certain risk factors increase the possibility that a person will develop cancer. Some cancers occur as a direct result of smoking, dietary influences, infectious agents or exposure to radiation (for example, ultraviolet radiation), while others may be a result of inherited genetic faults (AIHW (Australian Institute of Health and Welfare) and AACR (Australasian Association of Cancer Registries) 2008). Other risk factors include growing older, ionizing radiation, certain chemicals and other substances, certain hormones, alcohol, sedentary lifestyles or being overweight. Many of these risk factors can be avoided.

People diagnosed with cancer face many practical, emotional and psychosocial demands in addition to the effects of the disease and the physical treatment, as well as the anguish resulting from treatment. Some of these challenges include: coping with the shock of the diagnosis and fears about general health, wellbeing and the future; symptoms and adverse effects of treatment such as nausea, fatigue and physical changes in body appearance and functioning; changes in role and family functioning; financial costs, altered occupational, employment and financial status; psychological difficulties ranging from concerns about body image and sexuality to severe disorders such as anxiety and depression (National Breast Cancer Centre and National Cancer Control Initiative 2003). Evidence suggests that up to 66% of people with cancer experience long term psychological distress (Zabora et al. 2001); 30% experience clinically significant anxiety problems, and up to 20%-35% of people suffer from depression (Bodurka-Bervers et al. 2000). There is some evidence from studies of patients with breast cancer that depression is at least twice as common in people undergoing surgery for cancer as in those without cancer. Studies of patients with various cancer types also show that those who have undergone chemotherapy, adjuvant therapy or radiation therapy are at increased risk of depression (Jenkins, Carmody, and Rush 1998). Some studies report clinical depression in up to 40% of patients with progressive cancer in palliative care (National Breast Cancer Centre and National Cancer Control Initiative 2003). The level of distress and challenges may vary depending on the stages of cancer, cancer site, prognosis and patient burden (Zabora et al. 2001). Some patients need to deal with progressive illness and approaching death, while others face the physical, emotional and social challenges of survival (National Breast Cancer Centre and National Cancer Control Initiative 2003).

The impact of cancer, coping and emotional adjustment to the journey with cancer and survival vary with individual characteristics, and changes over time. Response to coping with the diagnosis of cancer and its after-effects are also influenced by several factors, for example, support from family and friends, religious beliefs, confidence in clinical diagnosis and treatment, age, gender, social circumstances, family commitment, attitudes towards health and illness, co-morbidity and so on. Descriptive data suggest that adjustment by patients with cancer is improved by

family and partner support, while criticism and overprotection by a spouse leads to negative mood and stress (Manne et al. 1999; Kuijer et al. 2000). Qualities of the relationship and the couple as a unit appear to be important. The level of stress experienced by partners of patients with cancer is also reported to be comparable to, or higher than, that of patients themselves (Baider and Denour 1999), and yet the partners receive less support. Restrictions to social activities are another challenge that many cancer patients face which often leads to depression. In addition to general detrimental effects on emotional well-being, living with cancer can pose specific problems that have a strong psychological impact, including body image and sexuality problems, interpersonal difficulties including new relationships post diagnosis, and anxiety, fear or concerns related to survival and recurrence. Concerns about current or potential sexuality problems have been identified as a major stressor (Kunkel et al. 2000) and as a source of anxiety (Corney et al. 1992).

Cultural and linguistic differences can play a significant role in how people cope with their cancer diagnosis and treatment. This issue is particularly significant for a multicultural country like Australia which has many diverse populations. Language barriers and lack of knowledge of the Australian health care system have been found to limit access of people from non-English speaking background to health information and health care services (National Breast Cancer Centre and National Cancer Control Initiative 2003). Thus, there is a need to be responsive to sensitive issues for different cultural groups. A report examining cultural issues relating to breast cancer identified several issues relevant to cancer diagnosis across a number of cultural groups. These included that many people prefer to see a medical professional of their own sex; many people view a diagnosis of cancer as a death sentence, regardless of the actual prognosis; a diagnosis of cancer is sometimes viewed as shameful; religion plays a fundamental role in many people's attitude toward their disease and treatment; and in many cultures, family and extended families play a central role in responding to major illness. Rights, responsibilities and decision-making are often shared by family members, and this influences the choice of treatment (National Breast Cancer Centre and National Cancer Control Initiative 2003).

Similar cultural issues for Aboriginal and Torres Strait Islander women with breast cancer have been identified including: high concerns about confidentiality; women's business and women's cancer; the significance of the concept of 'shame' for Aboriginal people (which is more than a sense of guilt or disgrace); family and kinship; the concept of 'support' among Aboriginal people; the perception of illness in terms of its impact on a person's ability to fulfil social and spiritual commitments (Morgan and Slade 1997).

## 4.2 Cancer in Australia

Cancer was the largest contributor to the total burden of disease in Australia in 2003. It is second overall among causes of death in Australia [Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR) 2004] and is the most feared disease for Australians, with over 60% of people nominating cancer as the illness they would most worry about getting, a fear that has increased over time (Borland, Donaghue, and Hill 1994). The Australian Institute of Health and Welfare (AIHW) reported over 100,000 new cases of cancer diagnosed in Australia in 2005. This number was projected by AIHW to grow by over 3,000 extra cases per year in 2006-2010. Although the growth is due primarily to the ageing of Australia's population, a small increase in the underlying cancer incidence rate has also been projected [AIHW (Australian Institute of Health and Welfare) and AACR (Australasian Association of Cancer Registries) 2008]. Major cancers causing most of the deaths in Australia are highlighted below:

**Table 1: 5 Most common causes of death from cancer in Australia, 2005**

Both Sexes	Percent of all cancer deaths (%)	Males	Percentage (%)	Females	Percentage (%)
Lung	19.0	Lung	21.4	Lung	15.9
Colorectal	10.7	Prostate	13.4	Breast	15.8
Unknown site	8.8	Colorectal	10.5	Colorectal	10.8
Prostate	7.5	Unknown site	8.3	Unknown site	9.5
Breast	7.0	Pancreas	4.4	Pancreas	6.2

**Source:** AIHW & AACR (2008). Cancer in Australia: An Overview, 2008. AIHW cat no. CAN 42. Canberra: AIHW (Cancer Series no. 46).

Deaths from lung cancer overtook breast cancer for the first time in 2005 when it became the most common cancer death for females. It has also been projected that lung cancer deaths in females will accelerate. This trend is caused by the increasing rates of smoking observed in women in the 1970s and 1980s [AIHW (Australian Institute of Health and Welfare) and AACR (Australasian Association of Cancer Registries) 2008]. Between 1991 and 2001, the incidence and mortality of lung cancer among males fell by an average of 2.1% per year. This decline is attributed to decreased tobacco smoking among men. However, lung cancer incidence among females increased by 1.2% and mortality by 1.1% per annum during this period, the result of which can be observed in their mortality rate [Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR) 2004].

Although lung cancer causes the most deaths among both males and females, breast (27%) and prostate (23%) were the most common cancers diagnosed in women and men respectively in 2005. The number of new breast cancer cases in women has more than doubled over the 25-year period from 1982 to 2006. The number of cases diagnosed in 2006 was 3% higher than the number diagnosed in the previous year and is the largest number of new breast cancer cases in women reported in any year to date. The age-standardised incidence of breast cancer rose from 100.4 cases per 100,000 in 1991 to 112.4 cases per 100,000 in 2006 (Australian Institute of Health and Welfare 2008). The breast cancer incidence rate increased 1.4% per annum on average between 1991 and 2006. However, mortality rate from breast cancer has declined by an average of 2.2% per year during this period [Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR) 2004].

With respect to prostate cancer, the reported incidence was relatively stable until 1989 but there was a dramatic rise in the number of new cases in Australia between 1990 and 1994. Following a peak between 1994 and 1997, the age-standardised incidence rate fell by 30%, then stabilised in 1998 and 2000 (The Cancer Council Australia 2004). Prostate cancer accounted for over 29% of all diagnoses in 2005

[AIHW ( Australian Institute of Health and Welfare) and AACR (Australasian Association of Cancer Registries) 2008].

#### **4.2.1 Cancer and Aboriginal Australians**

The pattern of cancer is different for Aboriginal Australians. It is well-known and well-documented that Aboriginal people have the worst health status as a n identifiable group in Australia (Couzos and Murray 2003; Cunningham et al. 2008; Thomson 2003; Western Australia Joint Planning Forum on Aboriginal Health 2000). Their poor health is characterised by a range of communicable and chronic diseases, with cancer one of the three prioritised chronic diseases referred to in the National Aboriginal and Torres Strait Islander Health Strategy in 2001 (Condon et al. 2003).

##### ***Epidemiological Data***

Cancer was not considered a priority health issue for Aboriginal and Torres Strait Islander Australians before 2001 (Thomson 2000). This may be because of their well documented and more immediate health problems, the lower incidence rates of many common cancers diagnosed among non-Aboriginal people (with the notable exceptions of smoking-related cancers), and limitations both in the availability of cancer statistics and understanding. However, health concerns with regard to cancer are increasing. Aboriginal Australians are twice as likely to die from cancer compared to non-Aboriginal Australians. Cancer is reported as the third most frequent cause of death in Aboriginal women, after death from cardiovascular and respiratory diseases [AIHW (Australian Institute of Health and Welfare) and AACR (Australasian Association of Cancer Registries) 2008].

Epidemiological information regarding cancer among the Australian Aboriginal population is limited, and is only recently beginning to be comprehensively documented (Condon 2004; Coory, Thompson, and Ganguly 2000; School of Public Health and Tropical Medicine 2002). Most of the data are also likely to be influenced by under-ascertainment of the Aboriginal population as a result of inaccurate

identification and misclassification of Aboriginal status. Under-ascertainment of Indigenous cancers also occurs as a result of factors such as lower rates of autopsy for Indigenous persons (Threlfall and Thompson 2009). According to Cunningham (2008), until 2001 there was little information on cancer incidence, diagnosis, treatment, and survival, or on time patterns in this population. In Australia, population-based cancer registries collect data and consistently publish reports on cancer incidence, mortality and survival rates. Clinical cancer registries in specialist cancer treatment centres monitor diagnoses, treatment, complications and outcome. National cancer control programmes, operating in all states and territories, provide information on cancer prevention and early detection programmes. Nonetheless, no national level information is available for Aboriginal and Torres Strait Islander people regarding cancer disease experience. Neither the Australian Institute of Health and Welfare (AIHW) nor the Australian Bureau of Statistics (ABS) publishes specific race and ethnicity data on cancer. It is difficult, therefore, to know the cancer status for Aboriginal people at national level. This generates an erroneous impression that cancer does not have a great impact on Aboriginal and Torres Strait Islander people (Thomson 2003). Although national level disaggregated data is still unavailable for Aboriginal and Torres Strait Islander people, improvements regarding the availability of information have occurred over the last ten years, especially in Queensland, New South Wales and in the Northern Territory. A more complete picture of cancer occurrence, causation, and control in Indigenous Australians can now be presented (Cunningham et al. 2008).

### ***Cancer Incidence***

As previously mentioned, no national cancer incidence statistics are published for Aboriginal Australians because cancer registries in most of the states do not accurately record Aboriginal status. For example, Condon et al., (2005) noted that the NT Aboriginal incidence rates reported in their study under-estimate actual cancer incidence by approximately 15-20% because of a small degree of under-ascertainment of cases and misclassification of Aboriginal status in the Northern Territory Cancer Registry (Condon et al. 2003). The Western Australian Cancer Registry has reported Aboriginal incidence rates, but in 1996 and 1997, 17-18% of cancer registrations were missing data on Aboriginal status (Thomson and Irvine



2001). A another report related to WA and South Australia (SA) indicated that the under-reporting is more likely to be in the range of 25-30% and 30-35% respectively (Threlfall and Thompson 2009).

Data quality is improving, however especially in the NT. A thorough assessment of data quality has recently been completed for the Northern Territory Cancer Registry, including re-screening of notification sources. For patients diagnosed in the period 1991-2001, case ascertainment was estimated to be over 95% complete with a small degree of misclassification of Aboriginal status (only 5%) (Condon, Armstrong et al. 2005). It is important to recognise that this is the result of intense efforts by stakeholders over recent years. Recent comparison of Indigenous and non-Indigenous age-specific cancer rates have been published using combined data from South Australia (SA), Western Australia (WA) and NT, as these jurisdictions are considered to have better Indigenous ascertainment in their hospital data than other jurisdictions (Threlfall and Thompson 2009). This publication has given the most detailed picture of Indigenous age-specific cancer incidence rates so far produced in Australia. Together these three jurisdictions constitute one-third of Australia's Indigenous population. More recent data from WA shows that the recording of Indigenous status in metropolitan hospital admission data has improved significantly since 2002, with under-reporting now less than 10% (Threlfall and Thompson 2009). New South Wales has also attempted to improve data quality on Indigenous cancer mortality (Supramaniam, Grindley, and Pulver 2006), but there is no indication that this effort has been continued. Queensland claims to have substantially improved its Indigenous identification over recent years, but this registering process has not been formally assessed (ABS 2005; AIHW (Australian Institute of Health and Welfare) 2005).

Although these quasi-national data need to be interpreted cautiously, they identify that incidence of cancer has a different pattern among Aboriginal people with several cancers such as liver, lung, pancreas, cervix, gallbladder and thyroid occurring more commonly. This indicates that preventive strategies and clinical care are not as effective as they could, and should be, for Aboriginal Australians (Condon 2004).

Incidence rates are generally lower for some cancers, for example, breast, prostate, bladder, kidney, bowel and skin melanoma. Comparative analysis of SA, WA and NT cancer statistics for Indigenous and non-Indigenous Australians has shown interesting differences:

**Pancreatic cancer** – The number of pancreatic cancers in the Indigenous population across three jurisdictions was low (12.7 per 100,000 populations) in 2007, although higher than for non-Indigenous people (10.8 per 100,000 populations) (Threlfall and Thompson 2009).

**Cervical cancer** – 8.8% of Aboriginal women compared with 3.2% of non-Aboriginal females have had cervical cancer (Thomson and Irvine 2001). The age-standardised rate per 100,000 for Indigenous Australians for three jurisdictions was 8.6, while the rate for non-Indigenous populations was 3.4. Cervical cancer is related to human papillomavirus (HPV) infection which may be associated with other sexually transmitted infections. The incidence of these infections has been very high in Central Australia. High rates of cervical cancer amongst older Indigenous women in NT and WA are particularly concerning.

**Liver cancer** – The incidence rate for Aboriginal males was 3.6 times that of non-Aboriginal males, and 3.8 times that for non-Aboriginal females. Jurisdiction-combined age-standardised rate per 100,000 was 10.9 for Indigenous people and 4.5 for non-Indigenous populations. It is one of the most significant cancers in Indigenous populations. The high incidence rate is largely attributable to high rates of hepatitis B infection and excessive alcohol consumption in some males (Threlfall and Thompson 2009).

**Breast cancer** – Although generally incidence rates of female breast cancer were lower in Indigenous communities, in SA it was the second most common cancer in Indigenous persons. Jurisdiction-combined age-standardised rates for Indigenous and non-Indigenous people were 34.1 and 63.0 respectively (Threlfall and Thompson 2009).

**Prostate cancer** – The combined jurisdiction age-standardised rate per 100,000 for prostate cancer was 17.4 (Indigenous) and 77.9 (non-Indigenous). Low participation

rates of Indigenous men in P SA testing for prostate cancer contribute to lower Indigenous incidence rates (Threlfall and Thompson 2009).

Colorectal cancer – Colorectal cancer was the third most common cancer in Indigenous persons and the second most common cancer in non-Indigenous persons in SA. This could be due to the long history of colorectal cancer screening in this state. The jurisdiction-combined rate was 29.9 for Indigenous and 64.7 for non-Indigenous Australians (Threlfall and Thompson 2009).

Lung cancer – Lung cancer was the most common cancer in Indigenous persons in WA, SA and NT. The age-standardised rate per 100,000 Indigenous population (2002-06) with 95% confidence interval was 74.8 compared with the non-Indigenous rate which was 47.1. This cancer was significantly higher in the Indigenous population than in the non-Indigenous population in the 50 -64 years age groups (Threlfall and Thompson 2009). Condon has reported that lung cancer incidence is higher in Aboriginal people in the NT at all ages, but particularly for people (aged 0-64 years) (Condon et al. 2004).

Unknown primary site – Cancer of unknown primary site was the fourth most common cancer in Indigenous persons in SA, and around twice as high for Aboriginal than non-Aboriginal people in WA (Thomson and Irvine 2001). The jurisdiction-combined age-standardised rate per 100,000 was 42.9 compared to the non-Indigenous rate of 15.8. Smoking is the major risk factor and it has been found that half of all cases have had a current or past smoking history. Late stage presentation of cancer, and poor or delayed access to diagnostic and treatment services may also be responsible for this higher rate (Threlfall and Thompson 2009).

The Aboriginal cancer incidence rates in the NT were also higher than total Australian rates for cancers of the liver, gallbladder, cervix, vulva and thyroid, and in younger people only, for cancers of the oropharynx, oesophagus, pancreas and lung (Condon, Armstrong et al. 2005).

Despite lower incidence rates, it is evident from research findings from some states (especially NT) that the incidence and mortality rates for the cancers previously thought to be non-threatening are increasing among Aboriginal people, and some of

these increases are statistically significant. In the NT, Aboriginal incidence and deaths from pancreas and breast cancer increased by more than 200% between 1991 and 2001, and there were no cancers for which large falls were recorded. This has been a real increase, and could be associated with increasing levels of obesity or the considerable fall in fertility rates. The high incidence of lung and liver cancer is consistent with high prevalence of smoking and hepatitis B amongst Aboriginal people, while the high incidence of cervical cancer may be related to lower Pap test coverage or to a higher prevalence of infection with HPV (Condon, Armstrong et al. 2005).

### ***Cancer Mortality***

High death rates from cancer occur among the Aboriginal people of Australia. In WA during the period 1997-2000, the age-standardised death rates were almost double for Aboriginal people than those of their non-Aboriginal counterparts (Thomson 2003). For every 100 cases of cancer diagnosed among Aboriginal males during 1993-1997, there were 73 deaths, compared with only 47 deaths for every 100 cases diagnosed among non-Aboriginal males. For Aboriginal females, there were 52 deaths compared with 43 for every 100 diagnoses in non-Aboriginal females.

The picture is similar to the Northern Territory (Thomson 2003). Between 1977 and 2000, cancer mortality in the NT Aboriginal population increased for eight cancer sites and fell for three. The rise was statistically significant for cancers of the oropharynx, lung and pancreas. Lung cancer was by far the most common registered cause of cancer death with mortality from this cancer doubling between 1977 and 2000. Mortality rates in the NT Aboriginal population for all smoking-related cancers more than doubled from 57.4 per 100,000 in 1977-1982 to 117.3 per 100,000 in 1997-2000, showing a greater increase than mortality rates for all non-smoking-related cancers combined (Condon et al. 2004).

The following table shows that even when Indigenous incidence rates are lower than non-Indigenous rates, mortality rates are higher than non-Indigenous rates. For the

combined data the mortality, incidence ratio for Indigenous persons is 70% higher than that of non-indigenous persons (Threlfall and Thompson 2009).

**Table 2: Age-standardised incidence and mortality rates for the combined and individual jurisdictions**

	Incidence rate	Mortality rate	Mort: Inc ratio
Indigenous combined	392	261	0.67
Non-Indigenous combined	503	195	0.39
Indigenous SA	327	204	0.62
Non-Indigenous SA	492	198	0.40
Indigenous WA	395	270	0.68
Non-Indigenous WA	514	196	0.38
Indigenous NT	423	280	0.66
Non-Indigenous NT	522	204	0.39

Source: Threlfall TJ, Thompson JR (2009). Cancer incidence and mortality in Western Australia, 2007. Department of Health, Western Australia, Perth. Statistical Series Number 86.

Threlfall and Thompson (2009) provided a list of cancers for which Indigenous persons have a much higher mortality rate than non-Indigenous persons, including lung (2x), unknown primary (3x), lip/mouth/pharynx (4x), pancreas (1.5x), liver (3x), cervix (5x) and uterus (2x). Cancers where non-Indigenous persons have a higher mortality rate include colorectal (1.5x), prostate (3x), non-Hodgkin's Lymphoma (NHL) (2x), brain (3x), melanoma (6x) and kidney (3x). Cancers where the mortality rate is similar include female breast, stomach and bladder (Threlfall and Thompson 2009). Epidemiological data on specific cancer for Aboriginal communities in Queensland between 1982 and 1996 show that the death rate from cervical cancer among Aboriginal women was 13 times higher than the state average (Angus 2005).

The Australian Bureau of Statistics (ABS) reports that cancer accounted for 13% of Aboriginal female deaths between 1992-1994 and 1995-1997 with an age-adjusted mortality rate of 1.4 times that of non-Aboriginal females. According to Thomson & Biscoe (1991), cervical cancer alone was responsible for 4.9% of the excess mortality for Aboriginal women in Queensland (Kirk et al. 1999). Lower participation in cervical screening is one of the reasons for this disparity. The average participation rate was 41.5% in 1999-2000, which was 30% lower than that

for the rest of the state (Angus 2005; Coory, Thompson, and Ganguly 2000; O'Brien, Bailie, and Jelfs 2000). The incidence and death rates from cervical cancer have been gradually declining for all Australian women. Between 1982 and 2001, for women aged 20 to 69 years, the age-standardised mortality rate declined from 5.1 to 2.4 per 100,000 women (Australian Institute of Health and Welfare 2004). Cervical cancer deaths fell by 32% in the seven years following the introduction of the National Cervical Screening Programme (NCSP) in 1991 (School of Public Health and Tropical Medicine 2002).

In the Northern Territory, Indigenous mortality for lung and other smoking-related cancers more than doubled between the 1970s and 1990s (Condon et al. 2004). Furthermore, the incidence for several smoking-related cancers increased between 1991 and 2005, including cancer of the lip and oropharynx, stomach, and pancreas, but not for lung cancer (Zhang et al. 2008).

For several smoking-related cancers, the excess incidence and mortality in Indigenous people (compared with similar-aged Australians) is more noticeable in younger (<65 years) people (Condon et al. 2004). A Western Australian study also showed age differences in the relative risk of lung cancer (Gracey, Williams, and Smith 2000). Although colorectal cancer is comparatively less common in Indigenous people than in other Australians, both incidence and mortality rate ratios are higher in younger rather than older Indigenous people in the Northern Territory (Condon, Armstrong et al. 2005; Condon et al. 2004). These findings support the generation-based increases in exposure to risk factors, such as smoking, diet, and physical activity (Cunningham et al. 2008).

### ***Cancer Survival***

Five-year cancer survival can be used as an approximate indicator of disease cure rates. Data from SA, Queensland (Valery et al. 2006) and NT (Condon, Armstrong et al. 2005; Condon, Garling, and Lee 2006) have shown that cancer survival is worse for almost all cancers among the Aboriginal population. For thyroid and breast cancer, for example, the five-year survival rate for all Australians is over 90 and

80%, respectively, compared with only 60 and 42% respectively for NT Aboriginal cases (Condon et al. 2004). Indigenous people diagnosed between 1997 and 2002 in Queensland were 1.5-times (95% CI 1.3–1.7) more likely to die from their cancer than non-Indigenous people after matching for cancer site, age, sex, year of diagnosis, and remoteness of residence (Valery et al. 2006). In the Northern Territory, Indigenous people diagnosed between 1991 and 2001 were 1.9-times (95% CI 1.7–2.1) more likely to die than other Australians after adjusting for cancer site, age, and sex (Condon, Armstrong et al. 2005).

In the NT, the incidence of breast cancer for Aboriginal women is one-third that of non-Aboriginal women, while death rates are similar. During 1987-1997, relative survival rates in the NT suggest that 61.2% of non-Aboriginal women survived 10 years after breast cancer diagnosis, while the figure is only 11.3% for Aboriginal women (School of Public Health and Tropical Medicine 2002).

The largest survival differences in percentage terms were observed for sites that had a high survival for all Australians. For example, 5-year Indigenous survival for thyroid, female breast, and cervical cancer was 69%, 56%, and 37%, respectively, compared with 95%, 85%, and 79% for all Australians combined (Condon, Garling, and Lee 2006). These cancers are amenable to early diagnosis, effective treatment and a high probability of cure. So improving the access, acceptability and quality of health care will increase the possibility of disease cure for Aboriginal people with these cancers.

Some studies have used data linkage to investigate specific cancer sites, treatments, and outcomes for Indigenous Australians. They report that compared with non-Indigenous people, Indigenous women had lower ovarian-cancer survival (Laurvick et al. 2003); Indigenous women with breast cancer were less likely to have reconstructive surgery (Hall and Holman 2003); Indigenous patients with lung cancer were less interested to receive surgical treatment (Hall, Holman, and Sheiner 2004); Indigenous patients with lung and prostate cancer were less likely to receive surgical treatment (Hall, Bulsara et al. 2004). Some of these disparities in cancer treatment

were partly explained by the lower socioeconomic status of Indigenous people but disparities were observed even after adjustment. None of the study findings presented adjustment at diagnosis. Thus, the recorded disparities might be explained to some extent by more advanced stage at diagnosis in Indigenous people (Cunningham et al. 2008). Other studies have reported that Indigenous patients in Western Australia with oral cancers spent longer in hospital while receiving treatment (Subramaniam et al. 2005) and Indigenous women with breast cancer in North Queensland were more likely to be diagnosed with advanced disease, although were just as likely to be considered suitable for breast conservation surgery (Shaw and Elston 2003).

Recent research suggests that the reduced Indigenous survival for some cancers results from Indigenous patients having more advanced disease when diagnosed and being less likely to receive specific cancer treatments although these factors do not fully explain their survival disadvantage (Condon, Barnes et al. 2005; Condon et al. 2006). This higher mortality ratio, with lower five-year survival rates and increasing incidence rates observed among Aboriginal people show that cancer is a worsening health problem for Aboriginal Australians.

Several patterns of cancer occurrence have been identified from the limited existing literature. There are some very pronounced differences in both age-specific and age-standardised cancer incidence and mortality rates between Indigenous and non-Indigenous populations in SA, WA and NT. While Indigenous Australians may have lower rates of cancer incidence for some cancers, the age-standardised mortality is 34% higher than non-Indigenous mortality rate for cancer. This means that proportionately more Indigenous people are dying from cancer than non-Indigenous people. Indigenous people have a lower five-year survival rate, higher incidence of some preventable cancers, late reporting and diagnosis of cancer incidence, and higher cancer incidence among younger people, meaning that cancer mortality is contributing to the shorter life-expectancy of Indigenous persons (Cunningham et al. 2008; Shahid and Thompson 2009; Valery et al. 2006).



### ***Pattern, Risk Factors and Management of Cancer***

Mortality from cancers of the lung, pancreas, mouth and throat in young people was several times higher than total Australians rates. This may be the outcome of comparatively higher levels of tobacco consumption by Aboriginal young adults in recent decades (Cunningham and Paradies 2000). The National Aboriginal and Torres Strait Islander Health Survey (2004-2005) published data on behavioural risk factors, including smoking, alcohol consumption, obesity, and dietary quality (ABS 2004). Age-standardised smoking statistics showed that Indigenous Australians were 2.2-times more likely to be current daily smokers. Over half of Indigenous adults in the survey smoked daily. The prevalence of smoking in Indigenous Australians was high across all age groups (although lower after 55 years of age), and there has been no noticeable decline in smoking rates since at least 1994 (ABS 2004). Smoking prevalence among Indigenous peoples varies widely and can be as high as 80% in some communities. A survey of children in Western Australia found that the mothers of a round 47% of Aboriginal children smoked during pregnancy (Zubrick et al. 2004).

Chronic infection with Hepatitis B Virus (HBV) and alcohol misuse are also significant key risk factors for the high rate of liver cancer among the Aboriginal population. Although a smaller proportion of Aboriginal Australians report consuming alcohol than do other Australians, for those who do, a very high proportion consume at dangerous levels (Condon 2004; Condon et al. 2003). In 2004-05, Indigenous people aged 18 years and over were more likely than non-Indigenous people to abstain from drinking alcohol. However, after adjusting for age differences between the Aboriginal and non-Aboriginal populations, the rates of chronic risky/high risk drinking were similar. One in six Aboriginal adults (16%) reported long-term (or chronic) risky/high risk alcohol consumption, increasing from 13% in 2001. In non-remote areas, the proportion of Aboriginal adults who drank at chronic risky/high risk levels increased from 12% in 2001 to 17% in 2004-05 (ABS 2008).

Data from the National Aboriginal and Torres Strait Islander Health Survey (2004-2005) also showed that Indigenous people were 1.2-times more likely to be overweight or obese; twice as likely to report no daily fruit intake; and 6.6-times more likely to report no daily vegetable intake than their non-Indigenous counterparts. Although data on physical activity are limited, 75% of Indigenous adults in non-remote areas were living sedentary life-style or had low levels of exercise in 2004-05. No information was available for Indigenous people who lived in remote areas (ABS 2004).

One study on the geographical disparity in risk of death from cervical cancer for Aboriginal women compared with non-Aboriginal women in Australia shows the risk of death from cervical cancer for Aboriginal women living in rural and remote areas to be about twice that for those living in metropolitan regions, while the trend for non-Aboriginal women is in the opposite direction. The authors speculate that the reason for these higher rates is poor access to and utilisation of screening services in rural and remote areas (O'Brien, Bailie, and Jelfs 2000). Although national data on Indigenous participation in cervical screening programme are not available from cervical screening registers, reliable screening participation estimates of the Northern Territory (Binns and Condon 2006) and Queensland (Coory et al. 2002) have shown that screening participation of Indigenous women in these areas is about two-thirds the national rate for all Australians.

Substantial variation however can be observed and participation in these screening tests has improved noticeably in some states (Binns and Condon 2006; Coory et al. 2002). Self-reported information on Pap smears tests from the 2004-05 National Survey reported that 52% of all female Indigenous respondents aged 18 years or more were having regular Pap smears. However, those in remote areas were more likely to report having regular Pap smears than those in non-remote areas (65% vs 47%, respectively). This may be because dedicated mobile cancer screening services visit those areas at certain time, and as a result a block of Indigenous women attend and are tested.

Hepatitis B virus (HBV) infection is common in Indigenous children, with a high proportion of Indigenous school children having serological markers of HBV infection, as reviewed by Condon and associates (Condon et al. 2003). Whereas chronic HBV infection for all Australians was estimated to range from 0.47% to 0.87%, on the basis of the prevalence of the marker hepatitis-B surface antigen (HBsAg), the prevalence in Indigenous Australians was around 2% in urban areas and 8% in rural areas (O'Sullivan et al. 2004). Information on risk factors such as the prevalence of Human Papilloma Virus (HPV) infection, sexual behaviour and cigarette smoking is not readily available by region and difficult to correlate with cancer rates.

Gastric ulcers and stomach cancers are strongly associated with *Helicobacter pylori*. Data from a small study in two Indigenous communities in Western Australia suggested the prevalence of *Helicobacter pylori* was 2–3-times higher in Indigenous residents than in the non-Indigenous population. The 91% of the Indigenous population in the remote or rural communities infected with *H. pylori* was equal to that reported in developing countries in South America and Africa. This study found that the bacterial infection was acquired in early childhood and, unless treated, apparently remains for life (Windsor et al. 2005). Further population-based studies are needed before these findings can be generalised.

Data on mammographic-screening participation are available for Indigenous women from the BreastScreen Australia programme. Participation by Aboriginal and Torres Strait Islander women (35.8%) was significantly lower than for non-Indigenous women (55.9%) (Australian Institute of Health and Welfare 2008). However, participation by Indigenous women has increased significantly from 31.8% in 1999–2000, the period of first reporting (Australian Institute of Health and Welfare 2008). In addition to lower initial participation, another study found that Indigenous women who attended for initial mammography screening were less likely than non-Indigenous women to attend for routine second-round screening or to continue regular screening after every two years (O'Byrne et al. 2000).

Mammographic-screening participation for Indigenous women varies by location. In Western Australia, the proportion of Indigenous women who participated in the breast screen programme increased from 62.0% to 66.9% over 2002-2003 and 2003-2004; however it was lower than that of non-Indigenous women (77.7% and 77.9%, respectively) in both years. Participation for rural Indigenous women was over twice as high as that for women from urban areas (49.0% and 18.6%, respectively) (BreastScreen WA 2007). By contrast, in Queensland, Indigenous women in metropolitan areas showed higher participation than other women (BreastScreen Queensland 2003). Although such geographical differences might be real, they might also be because of the variations in the quality of Indigenous identification.

In general, it is evident from the literature that Aboriginal people are diagnosed later and at a more advanced stage than that of their non-Aboriginal counterparts (Condon, Barnes et al. 2005). The reasons for this are unclear but presumably include the factors shown in Table 3 below.

**Table 3: Reasons for Late Diagnosis of Cancer among Aboriginal Australians**

<b>From health care system perspective</b>	<b>From individual and community perspective</b>
<ul style="list-style-type: none"> <li>- Few Aboriginal cancer specialists</li> <li>- Non-Aboriginal specialists' difficulty in communication with the patient and the family.</li> <li>- Paternalistic care</li> <li>- Less compliance with treatment</li> <li>- Lack of coordination between cancer centres, local hospitals and primary health care services</li> <li>- Rural location of many Aboriginal people and gaps in services</li> <li>- Unintentional treatment disparities.</li> </ul>	<ul style="list-style-type: none"> <li>- Sociocultural factors</li> <li>- Economic factors</li> <li>- Low rate of private health insurance</li> <li>- Cultural and religious barriers</li> <li>- Preference for different health care practices</li> <li>- Feelings of the immediate and extended family about the illness and disease.</li> <li>- Lack of culturally sensitive aftercare services.</li> <li>- Concerns regarding ineffective treatment, and feeling it is not worthwhile, especially for fatal cancers like lung cancer</li> <li>- Limited understanding of Aboriginal people about prognosis and treatment options</li> <li>- Absence of an informed community</li> <li>- Unfamiliarity with a hospital environment</li> <li>- The presence of other chronic diseases</li> <li>- Existing cultural and societal beliefs</li> <li>- Limited or inadequate medical resources</li> <li>- Fearful and fatalistic attitude towards cancer</li> </ul>

	- Fear of hospitals and the associated vulnerability to <i>white-man's</i> authority over the system
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**Source:** Derived from (Angus 2005; Condon 2004; Hall, Holman et al. 2004; Lowenthal, Grogan, and Kerrins 2005; Prior 2009)

The greater impact of cancer on Aboriginal people than on other Australians may be due to the limited availability and accessibility of existing health care services appropriate for them. Environmental, economic and educational barriers might be reasons in general, but there is undoubtedly a complex web of behavioural, cultural and social influences, which have been significantly influenced by decades of social disruption, discrimination, cultural dislocation, isolation and loss of power (Hunter 1993). Unconventional and unique beliefs and perceptions of health, wellbeing, disease and death may also influence individual care-seeking behaviour. However, none of these issues have been systematically researched or examined and a generalised understanding or conclusion cannot be drawn (School of Public Health and Tropical Medicine 2002; McDonald, Maguire, and Hoy 2003).

#### 4.2.2 National responses to disparity between Aboriginal and non-Aboriginal cancers

This section will highlight some of the national level responses to the most common and prevalent cancers in Aboriginal Australians.

Responding to the disparity between Aboriginal and non-Aboriginal Australians with respect to cancer, Cancer Council Australia convened the first national forum to discuss these issues in Darwin in August 2004. Various strategies were proposed to improve the poor cancer outcomes for Aboriginal people. Some of them are presented below:

On involvement and collaboration	On research
<ul style="list-style-type: none"> <li>- Invite Indigenous representatives to join Cancer Council's principal committees.</li> <li>- Factor Indigenous issues into policy development and promotion at every step in the cancer journey, from prevention to palliation.</li> <li>- Involve them in partnership with non-Indigenous health professionals.</li> <li>- Involve Indigenous people in service design and delivery of cancer screening programmes.</li> <li>- Increase collaboration</li> </ul>	<ul style="list-style-type: none"> <li>- Boost research on cancer among Indigenous people.</li> <li>- Enhance Indigenous ownership over the data.</li> </ul>

(Lowenthal, Grogan, and Kerrins 2005)

At the Darwin Forum, Cancer Councils around Australia recognised that Aboriginal people had been under-serviced by their agencies and that the problems, issues and understandings of Aboriginal people had not been adequately addressed. They committed to increase support for Aboriginal people at State and Territory level. The Cancer Council of Australia examined educational tools to assist in the management of pain, dying and death among Aboriginal communities. They also initiated a process to increase Aboriginal participation in the whole course of cancer prevention, screening, palliation, treatment and support services. The Cancer Council NSW and Queensland employed an Aboriginal Liaison Officer and released a cancer information kit for Aboriginal Health Workers (Lowenthal, Grogan, and Kerrins 2005). The Cancer Councils are reportedly pushing state and federal governments to recognise that cancer is a significant cause of morbidity and mortality in Aboriginal

people and to ensure there is provision of high quality and culturally-appropriate cancer prevention, detection, treatment care and support services for Aboriginal people (The Cancer Council NSW January 2008).

Cancer Council NSW has taken initiatives regarding tobacco control in Aboriginal communities. It is participating in a research project with the Aboriginal Health and Medical Research Council (AH&MRC), the Australian Respiratory Council, and NSW Health amongst others, which aims to reduce smoking-related disease and morbidity in Aboriginal communities. The project is trialling an intervention that includes the employment of specialist tobacco control workers within Aboriginal Community Controlled Health Services in NSW. Moreover, the Aboriginal community is a target population of The Cancer Council NSW Tobacco and Social Equity Strategy. Part of this strategy includes campaigning for the free provision of nicotine replacement therapy to socially disadvantaged people via agencies which have been trained in appropriate nicotine cessation methods (The Cancer Council NSW January 2008).

Cancer Council Victoria has undertaken a number of initiatives to spread the word about cancer prevention and early detection in the Victorian Aboriginal community. These include: developing a range of culturally appropriate resources (all resources use local Indigenous artwork, are developed in consultation with community members and are provided free of charge to Aboriginal health services); training Aboriginal Health Workers about the importance of cancer prevention; organising and hosting cancer awareness forums in the community; working with Aboriginal health services; and employment of staff dedicated to coordinating Aboriginal Education and Tobacco Control Programmes (Cancer Council Victoria 2008)

Cancer Council Queensland has been working with an advisory group of Aboriginal and Torres Strait Islander stakeholders to develop services and resources to improve the care of Aboriginal people with cancer in Queensland. An important part of this work is the education of Aboriginal Health Workers through a Cancer Care Course. This is a skills and information course about cancer, offered bi-annually. Content of

the course includes 'what is cancer', 'prevention and early detection of cancer', 'cancer treatment', 'management of side effects of treatment', 'palliative care', 'psychosocial care for patients and families' and 'support services' (Cancer Council Queensland 2009).

The National Cervical Screening Programme identified and has begun to address the barriers to accessing cervical screening among Aboriginal women (Australian Government Department of Health and Ageing, Population Health Division, 2001). The approach includes enhancing knowledge about the screening process; addressing the issue of fear of pain during screening; addressing concerns about lack of confidentiality, feelings of shame and embarrassment, and fear of having an abnormality detected. Addressing these issues as well as highlighting the potential benefits of screening, aim to create a service that would be Aboriginal-specific, culturally safe and comfortable for the participants (Coory, Thompson, and Ganguly 2000).

The National Tobacco Strategy 2004-2009 aimed to decrease tobacco consumption in order to reduce smoking-related cancers. The objectives of the Strategy were, among all social groups: to prevent uptake of smoking; to encourage and assist smokers to quit as soon as possible; to eliminate harmful exposure to tobacco smoke among non-smokers; and where feasible, to reduce harm associated with continuing use of, and dependence on tobacco and nicotine (Ministerial Council on Drug Strategy 2004). Some of the policies undertaken include: regulation of tobacco marketing (promotion, place of sale, taxation, place of use, packaging and products); promotion of Quit and Smokefree messages; cessation services and treatment of tobacco dependence; strategies to address social determinants of health; tailoring of programmes to disadvantaged groups; community support and education; research, evaluation, monitoring and surveillance; and workforce development (Ministerial Council on Drug Strategy 2004). More recently, the Federal Government has committed substantial resources to tobacco-control in Aboriginal people through establishment of tobacco support workers and social marketing campaigns. As a continuation of previous initiatives more specific strategies have been spelled out in



the National Preventative Health Strategy 2010-2020. Some of them include: make tobacco products significantly more expensive; increase the frequency, reach and intensity of social marketing campaigns; design messages and place media to ensure reach with young smokers and socially disadvantaged groups; end all remaining forms of advertising and promotion of tobacco products; eliminate exposure to second-hand smoke in public places; regulate manufacturing and further regulate packaging and supply of tobacco products. The Government approach has been to work in partnership with Aboriginal groups to boost efforts to reduce smoking and exposure to tobacco among Aboriginal Australians. They plan to establish multi-component community-based tobacco control projects that are locally developed and delivered, and to enhance social marketing campaigns for Indigenous smokers ensuring a 'twin track'. Aboriginal specific campaign elements will be incorporated into the existing effective mainstream campaigns. They will provide training to Aboriginal and Torres Strait Islander Health Workers to improve skills in the provision of smoking cessation advice and in developing community-based tobacco control programmes. Specialist Tobacco Control Workers will be placed in ACCHS to build capacity at the local health service level to develop and deliver tobacco control activities. This strategy aims to boost efforts to discourage smoking among people in other highly disadvantaged groups; to assist parents and educators to discourage tobacco use and protect young people from second-hand smoke; to ensure that the public, media, politicians and other opinion leaders remain aware of the need for sustained and vigorous action to discourage tobacco use, and to ensure implementation and measure progress against and towards targets (The National Preventative Health Taskforce 2009).

The Second (2014–2018) and Third (2018–2020) phases of this strategy will include a continuing strong focus on population measures to discourage smoking, together with increasing emphasis on programmes and services for disadvantaged groups and continuing smokers who have been unable to quit (The National Preventative Health Taskforce 2009).

Chronic HBV infection is endemic among Aboriginal communities (Condon et al. 2004; Fisher and Huffam 2003) and can result in a high incidence of liver cancer. Prevention of chronic infection is the only effective strategy, as infection is usually acquired in infancy and early childhood. Hepatitis B vaccination in infancy is a key long-term prevention strategy. Hepatitis B vaccination commenced for Aboriginal children in 1987 and for all Australian children in 2000. Despite the availability of the vaccine, a significant proportion of Aboriginal children may still be at risk. A study in North Queensland found that only 44% of Aboriginal teenagers had completed HBV vaccination (Malcolm et al. 2000).

### ***Cancer control initiatives in Western Australia***

The Western Australian (WA) Government has proposed a model of care for rural and remote areas under the Cancer Outreach Programme. Under this model, specialist cancer services will be provided by the Cancer Centre in a regional town, with formal links to local health providers. Each service will have a state-wide cancer care coordinator or a nurse to guide the limits of service. For more remote and/or smaller communities, provision of services by telemedicine links has been highlighted. Connected issues such as Medicare billing, medico-legal protection and cross-state border registration are currently being considered (The WA Health Cancer Services Taskforce 2005).

Other initiatives planned by the WA Health Cancer Services Taskforce to facilitate the provision of cancer services in rural and regional WA include: the establishment of Tumour Collaboratives to provide formal multidisciplinary support across metropolitan, rural and remote regions, and the introduction of Cancer Nurse Coordinators across rural areas. Cancer Council WA is increasing patient support activity and will subsidise psychosocial support in rural areas. It will review workforce issues and identify gaps. The federal government has committed to a mentoring programme, linking metropolitan teaching hospitals to regional centres and promoting multidisciplinary care. Training/education of cancer specialists with a rural interest and up-skilling of regional generalists has been prioritised. Recent state government commitments include funding doctors in rural hospitals who have a

particular interest in cancer to act as lead cancer clinicians, provide outpatient services and educate GPs in dealing with cancer care. Improvements in communication are expected through the Tumour Collaboratives and tertiary cancer services. The Director of the Cancer Network works with the WA Country Health Service and South West Area Health Service to determine if travel and accommodation support can be improved or better tailored to suit country cancer patients. Information technology support, e.g. video-conferencing linked into Tumour Collaboratives and Cancer Units will be provided for rural and remote areas. Introduction of the Picture Archiving Compression System (PACS) has been identified as a priority, along with computer access to pathology results.

All of these initiatives are quite general and not much attention has been given to the specific issues for Aboriginal people with regard to cancer prevention and support services.

### ***Innovative Models/Approaches***

CanNET WA is focused on linking the metropolitan cancer services with the Greater Southern region of the state. The purpose of CanNET WA is to establish a Great Southern Cancer Service Network that is linked to other cancer centres and units, regional cancer units, and has good primary care engagement. Key achievements include the implementation of fortnightly multidisciplinary care meetings. These meetings use telehealth to link to tertiary metropolitan centres. Tumour-specific care pathways for common cancers have been mapped and will be used to help deliver consistent care as locally as possible. A state-wide directory of cancer services will be developed, the template of which will be rolled out nationally. Education is a strong focus, with visiting metropolitan specialists delivering sessions to health professionals in the Great Southern region. A programme has been implemented allowing nurses from the Great Southern region to spend time in tertiary settings to further develop their oncology skills (The WA Health Cancer Services Taskforce 2005).

Improving Aboriginal cancer outcomes and experience with cancer services has been prioritised in policy documents in WA. To improve knowledge of cancer and support for in the Community Controlled sector, the Cancer Network and Cancer Nurse Coordinators work with the ACCHS (The WA Health Cancer Services Taskforce 2005). It was also proposed that partnerships are formed with Aboriginal Health Services and communities at the regional level to develop strategies to promote holistic and culturally appropriate palliative care for Indigenous people. The document proposed that clinical care and support of Indigenous people, including the Aboriginal view of life-death-life as a continuum, spirituality, the importance of dying in country, and ceremonies and practices surrounding death would be included as a core component of education for health professionals (Department of Health 2005).

Cancer Council WA has started a number of initiatives for Aboriginal health professionals. *Programme of Experience in the Palliative Approach* (PEPA) provides primary health professionals - doctors, nurses, allied health professionals and Aboriginal Health Workers - with an opportunity to develop skills in the palliative approach by undertaking a supervised clinical attachment in a specialised palliative care service in Perth. They also run a Cancer Education Course for Aboriginal Health Professionals across metro, rural and regional Western Australia. The aims of this course are to increase the cancer knowledge of participants by providing practical information about cancer, treatment and the impact of the disease to improve the care of Aboriginal people with cancer (Cancer Council WA 2010).

## **4.3 Cancer among Indigenous populations in other Developed Countries**

### **4.3.1 Cancer among the Indigenous population of Canada**

Similar concerns regarding cancer among Indigenous people have been expressed elsewhere in the world. It has been recognised that in Canada, despite a myth of Indigenous people rarely getting cancer, the disease is now a leading cause of death. Canada's Indigenous population encompasses First Nations<sup>2</sup>, Aboriginal, Metis and Inuit peoples (Cancer Care Ontario 2004). Cancer is a significant cause of illness and death in First Nation populations, ranking third as a cause of death after heart disease and injury (Marrett and Chaudhury 2003). In the general population, incidence and mortality rates of cancer have been stable or declining for all cancers combined over the past decade. However, it is assumed based on past cancer trends and prevalence of risk factors in First Nations communities that cancer rates will increase among these groups of people over the coming decades (Cancer Care Ontario 2004).

A population-based study conducted by Marrett and Chaudhury (2003) described cancer incidence and mortality in Ontario First Nations (FN) over the period 1968-1991. The study identified some of the limitations of the previous studies published on cancer among Indigenous people in Canada, such as small numbers of cancers, different methods of identifying cancers in FN people, numerators and denominators derived from different sources, lack of currency in terms of the years studied, and restricted populations. All these factors restricted the generalisability and validity of the findings of previous research. The study conducted by Marrett and Chaudhury (2003) tried to overcome some of these drawbacks by including a longer time period and relying on files maintained by the federal government Department of Indian and Northern Affairs Canada to identify the cohort of FN people for the study. Population-based provincial cancer registries and vital statistics files were used to identify cancer events and to compare rates in the FN population with those of the general population. According to their findings, rates were lower for most types of cancer for the FN people including the most common (lung, colorectal, breast and

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<sup>2</sup> The term came into common usage in the 1970s to replace the word "Indian". However, no legal definition of it exists. Among its uses, the term refers to the Indian peoples in Canada, both status and non-status.

prostate). Exceptions include cervix, gallbladder and kidney for which FN people had increased incidence and mortality rates. According to the authors, the different distribution of cancer types and the increasing incidence of cancer are due to a combination of lifestyle, sociocultural factors and genes. Some of the prevalent risk factors are: high rates of smoking (79% of FN males and 72% of females are current smokers compared to 30% of all Ontario males and 27% of females); high levels of obesity; hormonal and reproductive factors (young age at first pregnancy and a greater number of children); low uptake of screening services; poor socioeconomic status and environmental contamination (Marrett and Chaudhury 2003).

In response to the trend of increasing cancer among Indigenous people, and with Canadian government funding, a new proposal entitled “*New beginnings: Planning Cancer care for Aboriginal peoples*”, was prepared (cited in Aboriginal Cancer Care Unit 2002) by the Joint Cancer Care Ontario-Aboriginal Cancer Committee in March 1997. This has served as a guide for all on-going cancer initiatives for Indigenous people in Canada. In 2000, the Aboriginal Cancer Care Unit (ACCU) was formed within Cancer Care Ontario, and is the principal body working on cancer issues for the First Nations Aboriginal People of Canada (Aboriginal Cancer Care Unit 2002; Marrett and Chaudhury 2003). The Unit has demonstrated a commitment to reduce the burden of cancer and improve quality of life through the promotion of traditional Indigenous methodologies, research, education, awareness, prevention and screening in Canadian Aboriginal people and their communities (Marrett and Chaudhury 2003). ACCU conducted a needs assessment to collect information on cancer-related needs of Aboriginal people in Ontario from the perspective of Aboriginal people and communities. A number of challenges specific for First Nations cancer control were identified:

- Life circumstances over which FN people have no control. This includes reserve systems which dictate where they can live, low quality housing, poor water quality, lack of resources, highly complex and fragmented health care system, etc.
- A myth that cancer is rare among FN people. This contributes to late diagnosis and misdiagnosis of cancer by health professionals

- Unavailability of culturally appropriate information about cancer
- The different age distribution of FN populations from the rest of Canada's population. FN people have a younger age distributions and higher birth rate.
- Unique and different concepts of disease management with a belief in a more holistic model of health
- Lack of research and cancer surveillance data specific to FN populations.

A report published by the ACCU (2002) highlighted the importance of Aboriginal people's opinions and views on cancer care. This was the first comprehensive study on the subject of cancer among Aboriginal people in Canada. Individual and group discussions were conducted with Aboriginal cancer patients, family members who have relatives with cancer, and community health workers (all together 229 individuals from 21 communities). The study also undertook questionnaire surveys of Aboriginal organisations and communities (participation rate of 87.2%), and among 50 health institutions (participation rate of 64.1%). Moreover, group meetings with cancer service providers and interviews with physicians and traditional healers were held (72 participated). The following themes were identified:

### ***Prevention and Screening***

*Aboriginal people's view of cancer:* Almost every person in most Aboriginal communities in Canada knew someone affected by cancer, which gives some idea of the impact of cancer and the widespread concern about it. However, there was a pessimistic attitude toward cancer in the communities. "The majority of respondents believed that a diagnosis of cancer was a death sentence, and only a small number thought cancer could be treated" (Aboriginal Cancer Care Unit 2002), p.7. Many of the respondents believed that "...cancer is inevitable, it is a matter of genetics or fate, or primarily caused by forces outside of their control, such as the environment, toxins in the food they eat, and the quality of life imposed on them by the reserve system." (Aboriginal Cancer Care Unit 2002). These views and attitudes had profound implications for Aboriginal people's receptiveness to, and participation in, prevention, early-diagnosis and treatment programmes on cancer, and they also

contributed to late diagnosis and the high mortality rate among Aboriginal people with cancer (Aboriginal Cancer Care Unit 2002).

*Education and awareness:* Most Aboriginal people were aware of cancer and they recognised the disease as a problem. However, they lacked basic information about symptoms or early warning signs; traditional healing methods; importance of healthy lifestyles and activities necessary to reduce the risk of cancer including routine screening, cancer diagnosis and treatment processes, treatment options and other services after diagnosis.

*Tobacco:* Two types of practice with tobacco among Aboriginal people were identified: traditional (sacred or ceremonial) use, and smoking or non-traditional use of commercial tobacco products. About half of the communities reported having offered teaching on the traditional uses of tobacco, however many of them were confused about these traditional practices and how smoking affected their health. Research showed that smoking of commercial cigarettes was high among the youth population. Community people recommended that ‘stop-smoking’ programmes should be culturally relevant, linguistically accessible, and include references to traditional uses of tobacco.

*Screening:* Although a large number of people reported access to cervical screening, community members seldom mentioned screening for prevention and early detection of cancer. Community members identified personal communication methods (workshops, community meetings and talking circles) as the most preferred mechanism for getting the message out to Aboriginal communities. They also mentioned that visual formats work best for the Aboriginal community. Education materials need to address specific Aboriginal concerns and include positive messages from Aboriginal people who have survived cancer.



## ***Treatment***

*Traditional healing:* Aboriginal people wished to access traditional healing methods, and it was not uncommon for patients to participate in both conventional and traditional treatment at the same time. The types of traditional practices included medicines, ceremonies and prayer. For historical and cultural reasons, some Aboriginal clients did not tell their physicians that they were also taking traditional treatments. This “hidden” use of traditional remedies could lead to problems such as negative drug-interactions. One interesting finding was that access to traditional healing in Aboriginal communities was lacking, especially in remote communities because most traditional healers were located in urban Aboriginal centres.

*Cultural appropriateness and sensitivity:* The need for cultural appropriateness of cancer services cut across all areas of service, from prevention, education and screening to treatment and palliative care.

Aboriginal people in Ontario reported the following:

- Cancer services in Ontario treated the “disease” and not the person.
- The “site specific” nature of the care was not compatible with their holistic views.
- The pace of care did not allow time for understanding, building trust or considering the need for decision-making by people with cancer and their families.
- Care facilities did not provide the option of including traditional foods, ceremonies or care.
- Services were not available in Aboriginal languages.
- Communication materials were not easily understood.
- Treatment was usually distant from the community and lacked cultural support.
- The accommodation was not appropriate for them to accommodate large extended family groups.
- There were insufficient Aboriginal medical and/or support staff.

*Research:* Community members wanted to see research on the types of cancers common amongst Aboriginal people, the possibility of hereditary links in various cancers, the impact of changes in the Aboriginal diet on cancer rates, the impact of the sorts of pollution common on or near Aboriginal communities. Moreover, there was a reported need for best-practice research to find a means to increase Aboriginal

participation in prevention and early detection activities (Aboriginal Cancer Care Unit 2002).

*Service Delivery Gap:* Significant gaps existed in conventional cancer service infrastructure that negatively affected the accessibility of cancer services to Aboriginal people. Many issues were related to costs of participation in treatment, absence of required services in rural and remote areas, and inadequate staffing including local capacity and knowledge in communities. Some of them are listed below:

### ***Gaps in Service Delivery***

- Lack of medical personnel and health service in rural and remote communities
- Laboratories and testing facilities only available in major urban centres
- Screening programmes did not reach most rural and remote Aboriginal communities
- Members of rural and remote communities had to travel significant distances to access the services
- Many remote communities not accessible by road
- Funding to assist the cost of travel for community people generally very inadequate
- Cancer clients especially had to bear significant costs to access services
- Many of the cancer clients could not afford the costs
- The network linking agencies providing services to Aboriginal communities was weak
- Less than one-third of the communities reported any contact with regional cancer centres
- Many of the on-site clinics were not staffed, or staffed only on a part time basis, with a high turnover rate
- Levels of training and responsibilities of community health workers varied from community to community
- Community workers were over-burdened with a range of duties and lacked the resources to provide effective cancer care information and support to their community members
- Financial assistance with cancer treatment was not applied equitably to all Aboriginal people

(Aboriginal Cancer Care Unit 2002)

Another study conducted by Hotson, Macdonald and Martin (2004) aimed to understand the issues of culture and remote service delivery in palliative care in selected FN communities in northern Manitoba. They identified cancer as the

primary diagnosis of palliative care patients. According to the study, health care providers felt that community members and other Northern providers were keen to participate in more palliative care. The study also identified some knowledge gaps and lack of understanding among and between health service providers and community members. Some of these are elaborated on below:

*On dying in the home country:* Most of the community members interviewed felt that most or all community members would prefer to die in their home community, while very few health care providers believed so. One respondent said that only elderly patients would prefer to die back home in the community and that younger patients might not accept palliation as a care option.

*On traditional beliefs and customs:* Few nurses or physicians were aware of any traditional customs in the community surrounding death or dying but about half of them believed that a patient would have access to traditional medicines, a healer or cultural ceremonies if they returned home for end-of-life care. On the other hand, many Aboriginal people reported that they did not believe in, or follow, traditional ways.

### **4.3.2 Cancer among Maori people of New Zealand**

Cancer is the second leading cause of death in New Zealand, accounting for 27% of deaths after heart disease, with substantial racial disparities (Ansley 2004). Maori and Pacific Islanders are the Indigenous people of New Zealand, comprising 21% of the total population. The overall incidence of cancer is higher in Maori than non-Maori people, and Maoris are 18% more likely to be diagnosed with cancer than non-Maori, and have a 93% higher mortality rate (Robson, Purdie, and Cormack 2005). Deaths from cancer are 51% and 78% higher respectively among Maori men and women in New Zealand. Cancer-specific survival is lower for Maori than non-Maori for most types of cancer (breast, cervix, prostate, colorectal, lung, uterus, kidney, leukaemia, etc) (Ministry of Health NZ 2005). Some types of cancer, especially smoking-related cancers such as lung cancer, are responsible for much of this excess. In 1996, registration rates with the Cancer Registry were considerably higher for Maori people for cancer of the liver, stomach, lung, cervix, pancreas, testis and breast, while others such as colorectal, melanoma, prostate, bladder, and brain were less common (Ansley 2004; Ministry of Health NZ 2005; New Zealand Health Strategy 2001).

These findings point to disparities between Maori and non-Maori in timely access to definitive diagnostic procedures, staging procedures, and optimal treatment or management of cancer. In light of this reality, in 2001 the Public Health Directorate of the Ministry of Health involved the New Zealand Cancer Control Trust to scope a plan for the development of a Cancer Control Strategy. In 2003, the New Zealand Cancer Control Strategy was released (Ministry of Health NZ, 2005). The Strategy has given special attention to reducing the incidence and impact of cancer on the Maori population in New Zealand and reducing inequalities with respect to the disease. This is consistent with obligations under the Treaty of Waitangi to ensure equity of access and outcome for Maori people (Ministry of Health NZ 2005).

Some features of cancer among Maori and other Indigenous people in New Zealand are summarised below:

- Research conducted on ethnic inequalities in cancer survival in New Zealand showed lower survival for cancer of the breast, cervix, colon/rectum, lung, prostate and uterus among Maori than non-Maori/ non-Pacific people at many sites (Jeffreys et al. 2005).
- Maori people, together with Pacific and Asian peoples in New Zealand, experience higher rates of carriage of hepatitis B surface antigen (HBsAg), causing an excess rate of hepatocellular cancer.
- These groups also experience a higher seroprevalence of *Helicobacter pylori* infection, a major risk factor for stomach cancer.
- Maori have the highest percentage of people who smoke regularly (41.4%) compared to the New Zealand average (21.9%).
- NZ now has the 3rd highest rate of obesity (aged 15 and over) of any country in the world after the USA and Mexico, a dramatic change over a short period of time. Māori children are over-represented in the most deprived groups that have a higher rate of obesity (National Māori Coalition of Cancer Services and Forum Steering Group 2009).
- Harris et al. discuss the effects of a key root cause—racism—based on data from the 2002/ 2003 National Health Survey. Data showed ‘that self-reported experience of racial discrimination was highest among Maori and that any such experience was strongly associated with negative health effects equally for all ethnic groups’ (Harris et al. 2006), p.2006.
- Maori and Pacific women with breast cancer often present late or are at a more advanced stage when diagnosed. Maori and Pacific women are also quite reluctant to use cervical screening services. Causes are attributed to costs, language and cultural barriers, insufficient knowledge or high mobility and frequent changes of address (Jameson, Sligo, and Comrie 1999).
- In a study of Maori women who developed invasive cervical cancer, the main underlying factor was the absence of cervical screening or infrequent smear tests (New Zealand Health Strategy 2001).

The Ministry of Health NZ, as part of the development and implementation of a comprehensive cancer control programme, has undertaken further work to collect information on access to cancer services for Maori. A report, entitled *Access to Cancer Services for Maori* was published in February 2005 and has delivered a comprehensive understanding of issues relevant to access to cancer services for Maori. The study adopted a Kaupapa Maori framework that recognises the structural causes of inequality, such as unequal power structures, colonisation and institutional racism. This report identified three broad categories of factors that can be seen to influence Maori access to cancer services. They are summarised below:

#### Factors influencing Maori access to cancer services

<p>The cancer care system itself</p>	<ul style="list-style-type: none"> <li>• The way the system was funded, resourced</li> <li>• Physical facilities such as the capability of the rooms to accommodate all family members</li> <li>• The location of the services. For example, cancer services usually concentrated in metropolitan areas, which means that people had to travel for treatment which could involve high costs</li> <li>• The capacity of the cancer care workforce, including the number of Maori involved in the provision of cancer care services and the capacity of the mainstream cancer care workforce to respond to Maori needs and priorities</li> <li>• Lack of comprehensive, practical and appropriate information about cancer, full range of treatment options and service entitlements</li> <li>• The expense of cancer treatment.</li> </ul>
<p>Health care processes factors, meaning the way in which providers or organisations worked with each other and the processes that they had for support and rehabilitation.</p>	<ul style="list-style-type: none"> <li>• Existence of appropriate processes for working with Maori providers or other organisations in terms of comprehensive discharge planning</li> <li>• Issues around the training and sociocultural competence of the providers</li> <li>• Provider perceptions about Maori and cancer</li> <li>• Presentation of information that may impact on the interactions and communication with patients.</li> </ul>
<p>Patient level factors, meaning the association between various measures of socioeconomic position and access to services</p>	<ul style="list-style-type: none"> <li>• Demographic characteristics</li> <li>• Measures of wealth and deprivation that included family resources and resources within the community;</li> <li>• Access to private medical insurance</li> <li>• Access to transportation</li> <li>• Knowledge, attitudes and beliefs</li> <li>• Patients' decision-making/ preference factors.</li> </ul>

### 4.3.3 Cancer among Native Americans

The United States Census defines Native Americans as “any person having origins in the Indigenous peoples of North America and who maintain cultural identifications through tribal affiliations or community recognition”(Hampton 1998), p. 1689. In census 2000, 4.3 million people reported that they were American Indian/Alaska Natives (AIAN). They were living in all 50 states, with one-third on reservations and one-half in urban centres. This number included 2.4 million people who reported only American Indian or Alaska Native as their race (A National Action Plan for Cancer Survivorship: Native American Priorities). These people are the descendants of “more than 500 nations, each with unique culture, genetic and social demographic characteristics,” (Hampton 1998), p. 1689.

Cancer was once considered a rare disease among American Indian people. It was conceived as so rare that some authors suggested that American Indians never had cancer. The scenario has been changing since World War II. More strikingly within the past twenty years, almost every AIAN community has been experiencing “suffering and death from this dread disease” (Burhansstipanov and Hollow 2001). Life expectancy has increased for AIAN people by 39%, from 51 years in 1940 to 71 years in 1995, and this might be a partial explanation, as cancer is generally considered a disease of older age. However, AIANs have been experiencing a parallel increase in mortality rates. Cancer has been reported as the second leading cause of death for AIANs nationally and the leading cause of death among Alaska Natives (Paisano, Cobb, and Espey 2003). The cancer burden continues to escalate among AIAN, and importantly, Native Americans are not experiencing the decreases in cancer incidence that is occurring among other racial groups (Jemal et al. 2004).

Swan and colleagues utilised the Surveillance, Epidemiology and End Results (SEER) data, an authoritative programme of the National Cancer Institute on cancer incidence and survival in the United States, to explore the level and trends of cancer in the whole population and to assess the AIAN status within it. They showed that among all Americans, cancer incidence rates have been decreasing annually at 0.7% and death rates at 1.0% from 1992 to 2000. However, among AIAN populations,

although cancer incidence rates decreased in the same period (an estimated annual percentage change of 3.1%), the death rates demonstrated no significant change (Swan and Edwards 2003).

Some cancers that are relatively rare in the general population are still relatively common among Native populations, such as stomach, gallbladder and kidney cancer (Kaur 1999). The noteworthy incidence of kidney cancer has been observed in the SEER data for Alaska Native men (19.0 per 100,000 population) and in American Indian men living in New Mexico (15.6 per 100,000 population). Genetic, environmental and life style factors such as tobacco abuse, together can contribute to this high rate. According to the SEER data, carcinoma of the stomach is prevalent in both Alaska Native men (18.9 per 100,000 populations) and Southwestern Indian men (11.2 per 100,000 populations) with equivalent mortality rates (Hampton 1998). American Indians have the highest gallbladder cancer incidence rate (10.0 per 100,000 populations) of any racial group in the USA (Burhansstipanov 2001). Cancers which were previously uncommon among American Indians, for example breast and ovarian cancer, are increasing. Cancer occurrence has increased for some sites among this group for example, colorectal cancer due to changes in life-style (Kaur 1999).

A 2002 analysis of data from the nine SEER registries found some of the lowest survival rates for the AIAN population, including survival rates for all cancers combined. This study was the first known population-based comparison of cancer-specific survival and the relative risk of cancer death among the six major racial/ethnic groups in the USA. The analysis shows a wider variation among races for cancers with more effective treatment – breast, prostate and colorectal – and smaller differences for cancers with fewer options for treatment, such as lung cancer. They found that Native Americans had the lowest survival rates for prostate, lung and female colorectal cancers and the second lowest survival rates for breast and male colorectal cancers (Swan and Edwards 2003). According to the National Cancer Institute, approximately 63% of all AIAN breast cancer patients are alive five years after diagnosis (National Cancer Institute 2010). This is the poorest 5-year relative



survival of any ethnic and minority group in the US. In many geographic regions, accurate survival data are not available, resulting in the fact that the true impact of cancer in this population is still unknown (Burhansstipanov et al. 2010).

Various studies have highlighted regional variation in cancer incidence, mortality and survival rates in the USA (Becker et al. 2002; Burhansstipanov and Hollow 2001; Paisano, Cobb, and Espey 2003; Swan and Edwards 2003). Comparison of data from New Mexico and Alaska show that data on one AIAN population cannot be extrapolated to all descendants of the Indigenous people of North America (Burhansstipanov 2001). For instance, the overall cancer mortality rates were higher than the overall US rate (205.5 per 100,000 populations) in the Alaska (248.9) and the Northern Plains regions (291.7).

The excess mortality in these two regions was attributed to cancer of the lung, colorectum, liver, stomach and gallbladder. In contrast, the lung cancer mortality in the Southwest region was fourfold lower than the US rate. Similarly, cervical cancer mortality rates were higher among AIANs than among all racial/ethnic populations, particularly in the East and Northern Plains regions, and breast cancer mortality rates were lower in AIANs, particularly in the East, Pacific Coast and Southwest regions. The researchers recommended that plans or modifications for cancer prevention and treatment programmes should consider this regional variation and design programmes accordingly (Paisano, Cobb, and Espey 2003).

Problems of misclassification of AIAN status are consistently recognised in the US literature (Becker et al. 2002; Burhansstipanov 2001; Paisano, Cobb, and Espey 2003; Swan and Edwards 2003). The rates of misclassification range from nearly negligible to as much as 50% in several state registries (Swan and Edwards 2003). Racial misclassification is greater among urban dwelling AIAN, and according to the Department of Commerce, over 60% of the AIAN population reside in urban centres (Burhansstipanov 2001). One study evaluating the extent of racial misclassification of AIANs in the cancer registries for Idaho, Oregon and Washington states, found that 52% of cases were originally misclassified within the state registries as a race

other than AIAN, and 93% of the misclassified cases were coded as White. This type of misclassification threatens the validity of existing estimates of disease occurrence in this population, and the underestimation can also result in less emphasis being paid to disease control measures (Becker et al. 2002).

The issues, factors and behaviours that are associated with higher cancer risk have increased among AIAN population since World War II as summarised below:

**Tobacco:** Habitual tobacco users among American Indian men range from 20% in the Southwest to as high as 70% in the Northern Plains and Alaska (Burhansstipanov 2001; Hampton 1998).

**High-fat or high-calorie food consumption:** Almost half of AIAN population over age 45 are overweight or obese. The types of foods consumed by the AIAN in the past were primarily low in fat. Traditional food habits of AIAN people have been replaced by processed and commercially prepared foods, and their traditional cooking process over slow fires have been displaced by pan or deep frying methods (Burhansstipanov 2001).

**Alcohol:** Alcohol abuse is among the top health problems among AIAN nations, communities and organisations. Excessive alcohol intake causes a range of problems, including some forms of cancer.

**Sedentary lifestyle:** Many of the AIAN population lead a physically inactive lifestyle, which causes severe obesity and overweight problems among them.

**Poverty:** More than one-quarter (28%) of AIAN people of all ages live in poverty, more than twice the national average. Almost two-thirds (61%) of AIAN elders live in poverty.

**Late diagnosis of cancer:** Late diagnosis of cancer and diagnosis at an advanced stage are one of the issues among AIAN population in the USA. Health services themselves to some extent are responsible for this. The Indian Health Service (IHS) is the primary agency which provides services for AIANS. Burhansstipanov (2001) highlighted some of the features and problems of the IHS contracted health services:

- The IHS lacked sufficient budget, personnel, facilities and resources to provide high-quality, comprehensive cancer screening services to all urban and

reservation Indians. It could not offer services without collaboration from other agencies such as the Centre for Disease Control and Prevention and state health departments.

- The IHS had no oncologists or similar cancer specialists.
- The official federal policy regarding the IHS Contract Health Services was to place Indian patients on a “priority list” to transport them for follow-up services. However, the US Congress did not allocate funding for this. IHS policies were restricted by lack of funding, which created frustration for both providers and patients. Many American Indian elders waited on priority lists for months at a time until funding was available.
- Some AIAN people did not use the IHS due to unavailability or inaccessibility of a nearby IHS facility. Some chose convenience over culturally acceptable services.
- The prioritised areas for the IHS were infectious diseases and prenatal, infant, child and youth care. Elder health issues, such as cancer, remained a lower priority among most tribes and urban Indian clinics.
- Urban American Indians did not access IHS due to their perceived ineligibility for services provided by the Tribe and/ or inaccessibility of an IHS facility.

Some of the practical and cultural issues American Indian people in the USA face while accessing cancer services as identified by Burhansstipanov (2001) are summarised below:

- American Indian cancer patients may refuse to initiate treatment until they have participated in traditional Indian ceremonies. For urban residents, this means returning to their reservation and arranging a traditional Indian healer and ceremonies that often require many months of preparation.
- According to tribal policies, urban-dwelling Natives who have lived off the reservation for 6 months or more are typically ineligible for tribal health services, which means that the cancer patients must be served through Medicare or Indigent Care Services. However, the approval process for Medicare is long, and sometimes may take up to three months.

- Many tribal nations are concerned that during their years living on the reservation they have been exposed to environmental pollutants that may be responsible for the increase in cancer prevalence.
- After gaining access to screening programmes and enduring long waiting lists, cancer patients suffer from severe lack of funding for treatment programmes.
- Many tribes regard cancer as a white man's disease.
- People do not discuss it because they consider the disease as a form of punishment, shame and guilt for them.
- A few tribes consider the disease to be a condition for which the patient experiences physical challenges that may enable the rest of the tribal members to have fewer health problems. Thus, they consider it as a sacrifice in favour of the welfare of the other members of the community ("i.e. they wear the pain so that their community will be spared the pain").
- Some regard cancer as the result of a curse from someone, or a personal violation of tribal mores ("stepping on a frog, urinating on a spider") and so on.
- Some tribal beliefs regard an individual with cancer as being contagious with the cancer spirit and therefore others in the community ostracise that person.
- Some refuse surgery to treat cancer for fear that one's body and spirit may be missing a part after the surgery and therefore the individual can never find their ancestors when they move to "the other side", after death.

The same study also identified barriers to participation in cancer prevention and control programmes, such as:

- Inadequate policy and services
- Poverty
- Psychosocial (level of education, practices, and beliefs about health and disease; daily customs, lifestyles and beliefs; language or non-verbal communication styles; fear of using health services based on cultural practices or unpleasant past medical experiences; misconceptions about cancer; lack of cancer education)

- Sociocultural barriers (culturally irrelevant cancer education and recruitment materials; culturally specific beliefs and misconceptions about cancer)
- Information on cancer among AIAN has been lacking until recently and more needs to be done in terms of research, policy and strategy changes.

Initiatives are being taken to reduce misclassification, increase the generalisability of data and improve cancer services for AIAN in USA. Some are mentioned below:

- The Surveillance, Epidemiology and End Results (SEER) is an authoritative programme of the National Cancer Institute on cancer incidence and survival in the United States. In the past, this programme covered up to 12 registries in some states in the United States. It has currently been decided to expand to four more states in USA, which will cover 23% of African Americans, 40% of Hispanics, 42% of AIANs, 53% of Asians and 70% of Native Hawaiians and Pacific Islanders.
- Currently, all SEER registries are participating in a data linkage project with the IHS. This project is identifying additional cancer cases among American Indians, and the results will be reported back to the registries so that their databases can be updated (Swan and Edwards 2003). One such state-linkage study completed in Minnesota found that cancer rates for American Indians in that state were higher than prior estimates. For example, breast cancer rates were more than 3 times higher than the previous estimate (Kaur 1999).
- Projects are underway at the state and national levels to match key state vital records databases and the National Death Index with the IHS patient registration database so that persons who have been misclassified can be identified correctly (Paisano, Cobb, and Espey 2003).
- The National Cancer Institute is supporting a data linkage project for the Northwest Portland Area Indian Health Board, which is also addressing the issue of misclassification and developing software that can be used by other registries to improve reporting of Native American Status. In this case, the linkage is improving case identification by using tribal information (Swan and Edwards 2003).

- The Network for Cancer Control Research among American Indians and Alaska Native Populations, initiated in 1990 by the National Cancer Institute, has encouraged more research into cancers that are relatively rare (stomach, gallbladder and kidney) in the general population but disproportionately affect native populations (Kaur 1999).
- To address cancer issues among AIAN communities, the *National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives* was developed in 1992 by the “Network for Cancer Control Research among American Indian and Alaska Native Populations” and was published in a special National Cancer Institute Monograph. This plan informed both federal agencies and tribal leaders that cancer has become a major public health problem for AIAN, and that steps should be taken to inform them of this change in cancer epidemiology (Burhansstipanov 2001).

#### **4.4 Implications for Australia from other countries' experiences**

The government of each country has driven the processes for taking effective and appropriate initiatives on cancer among their Indigenous population. Each country's leading cancer organisations or units of organisations have supported the initiatives.

- Most of the countries have a central body that focuses on cancer issues for Indigenous people. For example, the Aboriginal Cancer Care Unit within Cancer Care Ontario, Canada is responsible for developing the Aboriginal Cancer Strategy and is based on a holistic approach to cancer prevention, screening and research. The Public Health Directorate of the Ministry of Health in New Zealand and the NZ Cancer Control Trust are working sensitively to improve Maori access to cancer care. The National Cancer Institute in the United States of America (USA) is working sensitively in Native American cancer issues.
- Canada and the USA emphasise the need for in-depth understanding of Indigenous people's opinions on their needs and necessities with regard to cancer. Moreover, the barriers to access to cancer care services have been identified, recommendations made as to how these could be addressed, and strategies adopted accordingly.
- Incorporating individuals' views regarding cancer and acknowledging its effect on people's care-seeking behaviour has been prioritised in each country, with the diversity of beliefs and attitudes explored through research at various levels.
- The initiatives of leading organisations and government of some countries, especially in Canada and the USA, are supported by good quality participatory action research and community-driven research. This research methodology is preferred by community members because it views people as stakeholders or equal partners and not simply as "participants" in all aspects of project development, implementation and evaluation (Burhansstipanov et al. 2001).
- Innovative prevention, screening, treatment and after care programmes and projects for Indigenous populations have been initiated by different agencies. For example, The Native American Cancer Survivors' Support Network, Spirit of Eagles: National Network for Cancer Control Research in AIAN Populations and Native American Indian/ Alaska Native Cancer Information Resource Center and

Learning Exchange (C.I.R.C.L.E.), all contribute to a project to establish a cancer information resource centre and learning exchange in the USA. In Canada, projects that have been successfully established are the Tobacco Wise Youth Action Project, the Aboriginal Relationship and Development Training Programme, and the Aboriginal Patient Navigator Pilot Programme. The Comprehensive Cancer Control Programme for Maoris is informed by a Kaupapa Maori framework in New Zealand.

- Specific data on race, ethnicity and socioeconomic status is available for each country and considerable effort has been expended to improve ascertainment of Indigenous status and analysis of the data.
- The absence of an in-depth understanding of the beliefs of Aboriginal Australians about cancer and knowledge of their cancer care experiences limits the capacity of health care providers and the health system to respond adequately to the evident disparities in cancer-related outcomes.



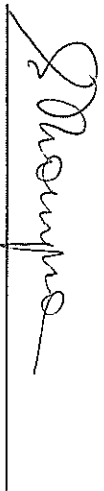
To Whom It May Concern

I, Professor Sandra Thompson, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia since it was started.

I coordinated the whole project, participated in the design and assisted with the conduct of the study. I actively participated in writing the paper published as:

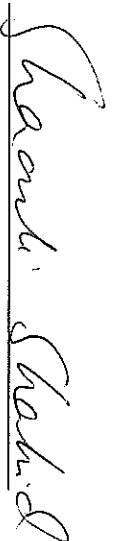
**Shahid S, Thompson SC. An overview of cancer and beliefs about the disease in Indigenous people of Australia, Canada, New Zealand and the United States. Aust N Z J Public Health 2009; 33(2):109-18.**

The writing of this paper was led by Shaouli Shahid. I commented upon drafts of this paper, assisted with responses to reviewers and approved the final version of the article.



(Signature of Co-Author)

Professor Sandra C Thompson



(Signature of Candidate)

Shaouli Shahid

# An overview of cancer and beliefs about the disease in Indigenous people of Australia, Canada, New Zealand and the US

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Increased longevity, Western lifestyle and food-habits have been associated with a steady increase in the diagnosed rates of cancer in most developed countries.\* In many of these countries, cancer is now the second major cause of death following cardiovascular disease,<sup>1,2</sup> and in Australia, cancer recently became the leading cause of mortality.<sup>3</sup> Cancer is also the most feared disease with more than 60% Australians nominating cancer as the illness they would most worry about getting, a concern that has increased over time.<sup>4,5</sup>

Historically, cancer has been considered a lesser problem for Indigenous<sup>1</sup> populations in Western countries,<sup>6-8</sup> probably due to their relatively short life-expectancy at birth,<sup>7,9,10</sup> other more immediate health problems<sup>11-15</sup> and the lower incidence of some cancers (with the notable exception of smoking-related cancers).<sup>11</sup> Moreover, lack of survival data<sup>16</sup> and under-ascertainment of Indigenous cancer cases due to misclassification of Indigenous status affect the accuracy of cancer data for these populations and may lead to cancer rates in Indigenous populations being underestimated.<sup>17-20</sup>

Progressive improvements in identification of Indigenous status and analysis of data<sup>19</sup> have shown that cancer is one of the leading causes of death among Aboriginal and Torres Strait Islander Australians, First Nations' Canadians,<sup>21</sup> Māori New Zealanders<sup>22</sup> and

\* In this paper, the term 'Indigenous' refers to Indigenous populations of Australia (Aboriginal and Torres Strait Islander people), Canada (Aboriginals, the First Nations and the Inuit and Metis people), New Zealand (Maoris) and the US (American Indian and Alaska Natives people).

the American Indian and Alaska Natives (AI/AN) communities in the US.<sup>6</sup> In Canada, First Nations populations cancer rates are increasing.<sup>23</sup> Cancer has a disproportionate impact on Māoris in New Zealand,<sup>24</sup> and in AI/AN communities in the US.<sup>25</sup> Reported mortality rates for cancer are markedly higher for Indigenous compared to non-Indigenous Australians.<sup>17,26,27</sup> Better understandings of the reasons underlying this are needed as a basis for more effective action.

This literature review explores the similarities and differences in Indigenous understanding and beliefs around cancer in Australia, Canada, New Zealand and the US. It also explores the situation regarding cancer among these populations in these four countries.

## Approach to literature search

Both epidemiological and in-depth qualitative studies were included in the literature search given the different nature of the two objectives. Published papers were selected from online searches of electronic databases such as Proquest, Google Scholar, Medline, Science Direct, Web of Knowledge and Informit. Key words used for epidemiological literature search were: 'Indigen\*' and cancer' and 'epidemiology', 'mortality', 'incidence', 'survival', 'Aborigin\*' and cancer and overview' for the four countries separately. 'First Nations', 'Māori' and 'American Indian and Alaska Natives' were also used in the search. Additionally, the Australian

## Abstract

**Objective:** Cancer among Indigenous populations in the developed world appears to have increased over past few decades. This article explores issues related to cancer among the Indigenous populations of Australia, Canada, New Zealand and the US and examines variations in the epidemiology, Indigenous peoples' perceptions about cancer and potential effects on care-seeking behaviour.

**Methods:** A search of peer-reviewed journal articles, government reports, published and unpublished theses and other grey literature was undertaken using electronic databases and citation snowballing. Both epidemiological and qualitative studies were included.

**Results:** Cancer in Indigenous populations in these four countries is characterised by high incidence and mortality rates for specific cancers and lower survival rates as a result of late diagnosis, lower participation and poorer compliance with treatment. A higher prevalence of many cancer risk factors occurs across these populations. Fear of death, fatalism, payback, shame and other spiritual and cultural issues are reported in the few qualitative studies examining Indigenous beliefs and understanding of cancer which undoubtedly influences participation in cancer screening and treatment.

**Conclusions and implications:** The holistic approach (physical, mental, emotional and spiritual) to healing and well-being, and the concept that individual, family and community are inseparable underpin Indigenous care-seeking behaviour. Further community-based research is needed to increase understanding of the needs of Indigenous people with cancer, and to guide policy and practice towards more supportive and effective care.

**Key words:** Health services, Indigenous; Neoplasms; culture; holistic health.

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Indigenous HealthInfoNet, homepages of the Australian Institute of Health and Welfare, the Australian Bureau of Statistics, Māori Health, Canadian Cancer Society, Aboriginal Cancer Care Unit and American Cancer Society provided useful information. Information from books, published and unpublished theses and grey literature including reports and published data from government agencies, non-government organisations and research centers, articles from non-peer reviewed journals were also identified through searches and citation snowballing and included if appropriate [24/47 were included]. Searches yielded a total of 1,061 initial results. These results were checked, and 203 were found relevant for consideration. This list was short-listed based on the relevance of the literature to the inclusion criteria, that is, if they contained information about Indigenous cancer incidence, mortality, survival, treatment, screening participation, risk factors or beliefs and perceptions of cancer and 119 were selected for this review. Publications were excluded if they: did not focus on one of the above-mentioned topics, did not concern Indigenous populations or were only policy papers and program descriptions. For searching the qualitative literature, 'Indigen\* cancer belief', 'Indigen\* and spirituality and cancer', 'perspectives on cancer' were used with the same search strategy and were articles assessed for methodological strength. There was surprisingly limited literature on Indigenous beliefs about cancer, with only five studies identified from the four countries for inclusion. There were two qualitative studies from Australia, and one from each of New Zealand, Canada and the US. Two studies were considered by the authors to meet the criteria for Level I (Generalisable) and three for Level III (Descriptive) qualitative research studies.<sup>28</sup>

## The burden of cancer in Indigenous populations in the four countries

### *Problems with the data*

The inadequacy until recently of identification of Indigenous status in health data collections and the lack of analysis of data by Indigenous status underpins the fact that Indigenous cancer issues were overlooked for many years.<sup>29</sup> Information regarding cancer among the Australian Indigenous population is beginning to be comprehensively documented in some jurisdictions.<sup>30,31</sup> However, most published research in Australia focuses on Aboriginal people living in rural and remote communities, or in Australian states where the majority of Aboriginal people do not live in urban areas, making the findings difficult to generalise to the whole population.<sup>32</sup> A dearth of Indigenous-specific research and cancer surveillance data is also noted in Canada where surveillance is now being prioritised based on acknowledgement that data is essential to providing clues to aetiology, assisting development of cancer control priorities and evaluating the outcomes and the effectiveness of cancer-related interventions.<sup>23</sup>

The problem of under-ascertainment of Indigenous identity has been reported in the literature of all four countries.<sup>6,16,22,27,33-35</sup> In the US, the rate of misclassification is estimated to range from nearly negligible to as much as 50% in several state registries.<sup>18,35</sup> Efforts

to improve data quality in some places are worthy of note. The Northern Territory Cancer Registry in Australia estimates that for patients diagnosed in the period 1991-2001, case ascertainment was over 95% complete with a small degree of misclassification of Aboriginal status (only 5%).<sup>36</sup> An updated cancer profile for the US described regional patterns of cancer in AI/AN populations by linking population-based state cancer registries from 1995 through 2004 with the Indian Health Services (IHS) patient registration databases. This process has diminished the effects of race misclassification in the US.<sup>19</sup>

Under-diagnosis of disease can also occur as a result of failure of Aboriginal patients to acknowledge symptoms and seek health care. It would also occur when there is inadequate diagnostic assessment or failure of appropriate death certification, but no evidence was found in the literature to suggest these causes. In Australia (data from other countries could not be found), a proportion (31.3 and 27.0 per 100,000 respectively among Aboriginal males and females, a rate ratio nearly double that of non-Indigenous males and females populations)<sup>12</sup> of cancers for which the primary site is not identified. Such issues need further exploration.

There are likely to be substantial differences in cancer incidence, outcomes and programs in Indigenous people across the states/provinces for countries as large as Australia, Canada and the US, so findings reported from one or several jurisdictions must be interpreted with caution where national data is unavailable.

### **Overview of Indigenous cancer epidemiology**

Notwithstanding these limitations, existing knowledge regarding cancer incidence, survival, mortality and cancer risk factors for the Indigenous populations of Australia, Canada, New Zealand and the US are summarised in Table 1 and 2. Although Indigenous populations have a similar or sometimes lower cancer incidence rates than the corresponding non-Indigenous population, the relative burden differs greatly between geographical locations.<sup>37</sup> Some common issues were identified for Indigenous people across the four countries. They are more likely to be diagnosed with cancer at a later stage of the disease;<sup>6,36</sup> have poorer survival rates;<sup>23,27,33,35,38</sup> increasing rates for some types of cancer;<sup>8</sup> higher rates of preventable and particularly smoking-related cancers;<sup>18,39,40</sup> and are less likely to have timely access to diagnostic methods<sup>41</sup> and continue cancer treatment than the non-Indigenous population.<sup>20,38</sup>

The literature also consistently reports a high prevalence of certain risk factors for cancer among the Indigenous populations in these countries: almost double the rate of smoking compared to the non-Indigenous population<sup>42,43</sup> higher rates of chronic viral hepatitis (B and C)<sup>44-49</sup> and alcohol abuse;<sup>50</sup> high levels of obesity and sedentary lifestyles;<sup>51</sup> lower uptake of cancer screening;<sup>17,52,53</sup> lower socio-economic status<sup>19</sup> and a higher proportion living in rural and remote areas which is a predictor for more advanced cancers at diagnosis.<sup>54,55</sup> The differing prevalence of these risk factors may partly explain why the incidence of cancer varies in Indigenous populations. However, it does not adequately explain

why Indigenous clients have delayed presentation with cancer, why they are less likely to access and continue treatment and the circumstances that surround their different treatment outcomes.

### **Indigenous beliefs about cancer**

Social cognition models attest to the importance of people's beliefs in determining their health-related actions. For example, the Health Belief Model suggests that individuals choose to participate in the health-related behaviour in order to reduce or prevent the chance of disease or early death. According to the Health Beliefs Model, there are two main beliefs that influence people's willingness to take preventive action: beliefs related to readiness to take action and beliefs related to modifying factors that facilitate or inhibit action.<sup>56</sup> Surprisingly, only six papers (five studies) exploring Indigenous psycho-social and cultural beliefs and perceptions about cancer were identified, showing that Indigenous beliefs about cancer and their effect on care-seeking behaviour has been largely neglected despite the possibility that such insights might assist in understanding the influences on Indigenous populations' decision-making about accessing cancer treatment and other services. Given the paucity of research in this area and that most studies have not utilised conceptual frameworks to recruit a diversified sample with thorough analysis and strong development of policy implications, caution in interpreting the findings is necessary.

Themes concerning Indigenous beliefs about cancer from the five qualitative research studies are summarised in Table 3. We selected supportive quotations to demonstrate that there are commonalities in beliefs across the four countries and some of these are distinct from Western beliefs. The literature also shows that Indigenous views, understanding and perspectives on cancer vary by geographical location and by community.<sup>7,15</sup> However, not all individuals from one tribe or community hold the same beliefs, particularly as Indigenous communities become more acculturated and exposed to a range of other beliefs including the biomedical paradigm.

Overall, the literature reveals a generally pessimistic attitude toward cancer in Indigenous communities, most people viewing it as a frightening disease associated with death.<sup>15,57</sup> A study from Canada found that the majority of respondents considered cancer as incurable, a death sentence where the mere mention of the word strikes fear into their heart.<sup>57</sup> Such views are also common among non-Indigenous people. One study from North America reported that "one of every three people regards a diagnosis of cancer as a death sentence" and that "there is a widespread belief that getting cancer is the worst thing that can happen to anyone."<sup>55</sup> In the general Australian population, cancer is also a highly feared disease,<sup>4</sup> showing this perception about cancer is shared by Indigenous and Western views.

Many Indigenous people retain their traditional belief system and may have little understanding of the biomedical underpinning of cancer as a disease.<sup>15</sup> Two of the five in-depth studies of Indigenous beliefs about cancer found that there was no word in Indigenous languages for cancer.<sup>15,39</sup> The belief that 'Indigenous

people do not or only rarely get cancer' may partly come from this fact. Limitations in understanding are not surprising in a population where the native tongue contains no word to indicate the phenomenon and explanations may only be given in English. The limited number of Indigenous-specific cancer resources<sup>29</sup> also contributes to a poorly developed understanding of Western biomedical knowledge of cancer.

Fear and a fatalistic view of cancer as a 'killer' are also understandable and are recognised concerns for all individuals faced with a cancer diagnosis.<sup>4,5</sup> The epidemiological data show Indigenous people are often diagnosed with cancer at an advanced stage and as a result die within a short period after diagnosis.<sup>38,41,58</sup> Therefore, few positive stories from cancer survivors are disseminated within communities to enhance understanding and confidence that cancer is not necessarily a death sentence. Another issue identified has been the reluctance by Indigenous people who had survived or were dealing with cancer to talk about cancer in their community.<sup>8</sup> Thus, the community generally sees only the dark side of cancer, while the reality that cancer can often be overcome with timely Western medical treatment is largely hidden. An individual with symptoms consistent with cancer may avoid presenting for assessment and diagnosis, preferring to hide their symptoms, believing the end is inevitable and wanting to postpone acknowledgement of it. Considering cancer as a Western concept and a white man's disease<sup>7,8</sup> may be one reason for a person feeling shame when faced with cancer. This may result in keeping the symptoms/diagnosis of cancer private and it not being reported until a late stage of the disease. Others may even ignore symptoms because they consider that they are not at risk for this disease.

Underlying beliefs of Indigenous people that cancer is caused by a curse put on a person for unlawful activity or wrongdoing can be another reason for late presentation. Such beliefs can bring additional stress to a patient who may be unwilling to talk about their disease for fear of bringing shame to the family and the community. This belief may also prevent them from accessing and continuing treatment.<sup>29</sup> McGrath and associates (2006) argue that attribution of 'payback' sometimes lead to acceptance of the disease, illustrated by the comment from one participant in their study: "may be that payback thing maybe they – some people might think its payback and that's why they accept, you know the death."<sup>15</sup>

Also reported is people's acceptance of their disease uncomplainingly and not accessing treatment if they think that they are bearing the pain on behalf of the family or the community, and thus, their suffering secures the safety and well-being of other members.<sup>6</sup>

Prior (2005) has shown how the belief that "cancer is contagious" can lead to "social and emotional isolation" for the person who has been diagnosed with the disease. She cited an example of a woman treated for breast cancer who described how her children shied away from touching her, even refusing to sweep up her hair that had fallen out.<sup>8</sup> Such social stigma can create fear and deter people from accessing screening or early detection services, let alone cancer treatments, as it is a disease that is tainted by the alienation it causes.

**Table 1: Age standardised cancer data for Indigenous populations across Australia, Canada, New Zealand and the US.**

Australia	Canada	New Zealand	US
<ul style="list-style-type: none"> <li>• Third leading cause of death among Australian Indigenous people.<sup>11</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Third cause of mortality among Aboriginal populations.<sup>43</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Second leading cause of death with substantial racial disparities.<sup>60</sup></li> <li>• Leading cause of death for Maori women and the second most frequent cause of death for Māori men.<sup>61</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Second leading cause of death for AI/AN nationally.<sup>34,62</sup></li> </ul>
<b>CANCER INCIDENCE</b>			
<b>General patterns of cancer incidence in Indigenous populations</b>			
<ul style="list-style-type: none"> <li>• Incidence rates of some common cancers are lower in Indigenous Australians than in the general population.<sup>17,30</sup></li> <li>• Proportion of cancers where primary site is unknown is high (31.3 and 27.0 respectively among males and females per 100,000 populations).<sup>12</sup></li> <li>• Incidence of preventable cancers is high.<sup>63</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Generally the risk of being diagnosed or dying with cancer is significantly lower in FN people.<sup>43</sup></li> <li>• High incidence rates for some less common cancer in the general population: cervix, gallbladder and kidney.<sup>43</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Māoris are 18% more likely to be diagnosed with cancer than non-Māori people.<sup>24</sup></li> <li>• Higher incidence of liver, stomach, lung, cervix, pancreas, testis, prostate, colorectal and breast cancers observed.<sup>24</sup></li> <li>• Study on pancreatic cancer showed that the incidence rate of pancreatic cancer in the total Māori population was significantly higher than in other Ethnic groups in NZ (<math>p &lt; 0.05</math>).<sup>64</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Cancer incidence rates in AI/AN populations for all cancers combined were lower than for non-Hispanic White populations for all regions combined.<sup>19</sup></li> <li>• Cancer incidence is high for stomach, gallbladder and kidney cancers.<sup>25</sup></li> <li>• Another study identified five most common cancers, i.e. prostate, lung/bronchus, colon/rectum, breast and cervix, in American Indians.<sup>40</sup></li> </ul>
<b>Regional variation in the data</b>			
<ul style="list-style-type: none"> <li>• Regional variations in rates observed.<sup>63</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Regional variations in rates observed.<sup>23</sup></li> </ul>		<ul style="list-style-type: none"> <li>• Incidence rates of cancer for AI/ANs varied by region<sup>34,46</sup> and by cancer site.<sup>19</sup></li> </ul>
<b>Cancer incidence in Indigenous men</b>			
<ul style="list-style-type: none"> <li>• High incidence rates observed in Indigenous men for cancers of lung, bronchus and trachea, mouth and throat, liver, pancreas, gallbladder, oesophagus and thyroid.<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Incidence is significantly lower in FN men for most common cancers (lung, prostate and colorectum).<sup>43</sup></li> <li>• Lung cancer is the most frequently occurring cancer in both FN and non-Indigenous male population.<sup>43</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Cancer incidence in Māori men is slightly lower than in non-Māori men.<sup>65</sup></li> <li>• Most common cancers in Māori men are: lung, stomach, prostate, colorectal, and testicular cancers (58% of all registrations).<sup>24,65</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Among AI/AN men, the top three cancers were prostate, lung, and colon and rectum for all regions except the Southwest, where the leading cancers were prostate, colon and rectum, and kidney.<sup>19</sup></li> </ul>
<b>Cancer incidence in Indigenous women</b>			
<ul style="list-style-type: none"> <li>• High incidence rates in Indigenous women for cancers of the cervix, lung, pancreas, liver and gallbladder, mouth and throat, oesophagus.<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>• In FN women, the incidence of cancers of the breast, uterus excluding cervix, colorectum and ovary are between 40% and 50% lower than that of in the general population.<sup>43</sup></li> <li>• Cervical cancer is higher among the FN population in Manitoba.<sup>23</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Cancer incidence (1996-2000) in Māori women is slightly higher than in non-Māori women.<sup>65</sup></li> <li>• Most common cancers in Māori women are: cancers of the lung, cervix, breast, colorectal and uterine,<sup>65</sup> representing 57% of all cancer registrations.<sup>24</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Among AI/AN women, the three top cancer sites were breast, lung, and colon and rectum in all regions except the Southwest, where the rate for uterine cancer ranked third.<sup>19</sup></li> </ul>
<b>Lower incidence of some cancers</b>			
<ul style="list-style-type: none"> <li>• Low incidence rates: breast, prostate, bladder, kidney, bowel, skin melanoma cancers.<sup>17,30</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Cervical cancer incidence has been declining in Ontario.<sup>23</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Less common: melanoma, colon, colorectal, bladder, brain and prostate cancers.<sup>24,65</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Lower incidence rates: leukemia, melanoma, and cancers of the bladder, brain, and testis.<sup>19</sup></li> </ul>
<b>Increased or increasing incidence rates</b>			
<ul style="list-style-type: none"> <li>• Substantial increase in the incidence of breast and colorectal cancers since 1991 but rates in 2005 were about 50% lower than the Australian incidence of these cancers.<sup>63</sup></li> <li>• Incidence of breast and pancreatic cancers reported to be increasing in NT between 1991 and 2001 at an alarming rate.<sup>36</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Overall incidence, while still well below the rate for the general population, is increasing in Aboriginal populations.<sup>43,62</sup></li> <li>• In Ontario, incidence in the FN population is increasing for all cancers combined and for the four most common cancers: breast, prostate, lung and colorectal.<sup>23</sup></li> <li>• Much of this increase is due to a rise in rates for colorectal and lung cancers.<sup>23</sup></li> </ul>		<ul style="list-style-type: none"> <li>• Gallbladder cancer is elevated in AI/AN men and women for all regions combined.<sup>19</sup></li> <li>• Liver cancer incidence is increasing consistently in AI/AN people compared with Non Hispanic White people for the period 1999 through 2004.<sup>19</sup></li> </ul>

*Continued over page>>>*

**Table 1: Age standardised cancer data for Indigenous populations across Australia, Canada, New Zealand and the US.**

Australia	Canada	New Zealand	US
<b>Smoking-related cancers</b>			
<ul style="list-style-type: none"> <li>Smoking-related cancer incidence are higher and are increasing in some States.<sup>17,31,36</sup></li> <li>Higher incidence and mortality in Indigenous people for smoking-related cancers is more apparent in younger (&lt;65 years) people.<sup>18,63</sup></li> </ul>	<ul style="list-style-type: none"> <li>Incidence of smoking-related cancer, especially lung cancer is increasing.<sup>39</sup></li> <li>High smoking prevalence may partly explain the relatively high rates of kidney, cervical and esophageal cancers.<sup>43</sup></li> </ul>	<ul style="list-style-type: none"> <li>The largest cancer rate differences between Maori and non-Māori were for cancers of the lung (an extra 30 per 100,000 among Māori compared to non-Maori).<sup>24</sup></li> </ul>	<ul style="list-style-type: none"> <li>In one study, lung cancer has been identified as the second most common cancer among both male and female American Indians.<sup>40</sup></li> </ul>
<b>CANCER MORTALITY</b>			
<b>General patterns of cancer mortality in Indigenous populations</b>			
<ul style="list-style-type: none"> <li>Cancer mortality generally significantly higher for Indigenous Australians than for other Australians.<sup>63</sup></li> <li>Indigenous Australians have 45% higher cancer death rates than other Australians.<sup>66</sup></li> <li>1.5 times as many cancer deaths among Indigenous males and females during 1999-2003 as was expected based on the rates in non-Indigenous Australians.<sup>11</sup></li> </ul>	<ul style="list-style-type: none"> <li>In British Columbia between 1991 and 2001 the mortality rate of Status Indians with cancer was 16.7% higher than non-Aboriginals.<sup>62</sup></li> <li>71% of cancer deaths in this population were for people under 75 years, as compared to 57.3% for non-Aboriginal people.<sup>62</sup></li> </ul>	<ul style="list-style-type: none"> <li>Deaths from cancer are 51% and 78% higher respectively among Māori men and women in New Zealand.<sup>24,61</sup></li> <li>An analysis of mortality data from national cancer registries for the 6-year period of 1996-2001 showed that cancer mortality in non-Māori people decreased substantially, but was increasing in Māori people.<sup>67</sup></li> </ul>	<ul style="list-style-type: none"> <li>Overall cancer mortality rate among AI/ANs was approximately 20% lower than the all-race rate in the US.<sup>68</sup></li> <li>ANs average annual mortality rate from cancer for the period 1994-1998 was 30% higher than that of US white populations, a statistically significant excess.<sup>69</sup></li> <li>Lung cancer is the leading cause of cancer death for AI/AN populations.<sup>34</sup></li> </ul>
<b>Cancers for which mortality was higher</b>			
<ul style="list-style-type: none"> <li>Cancer mortality was higher for specific sites: lung, liver, lip and oropharynx and cervix.<sup>63</sup></li> <li>Between 1994 and 2002, the cancer mortality rate of Aboriginal people was higher than that of the NSW population for oesophageal and stomach cancers in males and for kidney, cervical, lung and pancreatic cancers among females.<sup>70</sup></li> </ul>	<ul style="list-style-type: none"> <li>High mortality rates for cervix, gallbladder and kidney cancers.<sup>21,43</sup></li> </ul>	<ul style="list-style-type: none"> <li>Māoris have the highest mortality rates among all population groups for total malignant neoplasm and cancer of the lung, breast, prostate, colorectal, stomach, liver and cervix.<sup>24,65,71</sup></li> </ul>	<ul style="list-style-type: none"> <li>The seven leading sites for cancer death for AI/AN (both genders combined) were: lung/bronchus, colorectal, breast, liver, pancreas, stomach and prostate cancers.<sup>68</sup></li> <li>Increased mortality rates for smoking-related cancers, and cancers of the digestive system.<sup>69</sup></li> </ul>
<b>Cancers for which mortality was lower</b>			
<ul style="list-style-type: none"> <li>Low mortality for colon, rectum, kidney, prostate, melanoma cancers.<sup>29,30</sup></li> </ul>	<ul style="list-style-type: none"> <li>Lower mortality rates for most cancers in the FN population.<sup>43</sup></li> </ul>		
<b>CANCER SURVIVAL</b>			
<b>General patterns of cancer survival in Indigenous populations</b>			
<ul style="list-style-type: none"> <li>Survival is worse regardless of the stage of diagnosis.<sup>27</sup></li> <li>Lower five-year survival for all cancers combined.<sup>30,38</sup></li> </ul>	<ul style="list-style-type: none"> <li>Survival is significantly worse for all cancers combined for the FN people in Ontario but survival gap is not seen in British Columbia.<sup>23</sup></li> <li>Survival is significantly worse for prostate and breast cancers respectively in FN men and women than in the general population.<sup>23</sup></li> </ul>	<ul style="list-style-type: none"> <li>Survival is lower among Māori New Zealanders for most types of cancers (breast, cervix, prostate, colorectal, lung, uterus, kidney, leukemia) than for Non-Māori/non-Pacific people (adjusted for age at diagnosis).<sup>33,61,65</sup></li> </ul>	<ul style="list-style-type: none"> <li>AI/AN population have the lowest survival rates for all cancers combined among all races.<sup>35</sup></li> <li>Native Americans had the lowest survival for cancers of prostate, lung and female colorectal cancers and the second lowest survival rates for breast and male colorectal cancers.<sup>35,58</sup></li> </ul>
<b>Regional variation</b>			
<ul style="list-style-type: none"> <li>Regional variation in survival rates is observed.<sup>54</sup></li> </ul>	<ul style="list-style-type: none"> <li>Regional variation in survival from cancer is observed.<sup>23</sup></li> </ul>		<ul style="list-style-type: none"> <li>Survival rates from cancer exhibits regional differences.<sup>58</sup></li> </ul>
<b>Stage distribution at presentation</b>			
<ul style="list-style-type: none"> <li>For cancers of the colon and rectum, breast, cervix and non-Hodgkin lymphoma combined (adjusted for cancer site and age at diagnosis), 70% of Indigenous people were diagnosed with advanced disease (95% CI, 62%–78%) compared with 51% of non-Indigenous people (95% CI, 53%–59%).<sup>27</sup></li> </ul>	<ul style="list-style-type: none"> <li>Stage distribution at presentation appears similar for all cancers except for breast cancer, which is diagnosed at a later stage in FN women in British Columbia.<sup>23</sup></li> </ul>	<ul style="list-style-type: none"> <li>Māori people were much more likely to present with extensive disease than Caucasians for every tumor type.<sup>24,41</sup></li> <li>One study specific to breast cancer found that Māori women were more likely to have late-stage disease at clinical diagnosis.<sup>65</sup></li> </ul>	<ul style="list-style-type: none"> <li>AI/AN persons were less likely than Non Hispanic White people to be diagnosed at an early stage with localised cancer. The pattern varied by region and by cancer site.<sup>19</sup></li> <li>No difference was found in stage of disease at diagnosis between American Indians and other people in Montana.<sup>58</sup></li> </ul>

The belief is still widespread in some places that cancer is not a priority concern for Indigenous populations.<sup>57</sup> However, the opposite has also been found in some Indigenous communities: everyone knows someone who has been affected by cancer, either in friends or within their family, which shows the widespread impact of cancer.<sup>39</sup>

## Conclusion and implications

This review reveals similarities and differences in Indigenous cancer and cancer risk factors in Australia, Canada, New Zealand and the US. Rates of lung, liver, mouth and throat, cervical and other smoking-related cancers are high in Indigenous people.

**Table 2: Cancer risk-factors data for Indigenous populations across Australia, Canada, New Zealand and the US.**

Australia	Canada	New Zealand	US
<b>Smoking</b>			
<ul style="list-style-type: none"> <li>In 2004-05, 50% of the adult Indigenous population (51% men and 49% women) were current daily (or regular) smokers.<sup>12</sup></li> <li>While smoking rates have decreased slightly for the total Australian population over the ten years to 2004-05, there has been no significant change for that of the Indigenous population in this period.<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>Prevalence of cigarette smoking is high in Aboriginal populations.<sup>23</sup></li> <li>According to the Ontario FN regional health survey, 79% and 72% of on-reserve males and females reported being smokers, compared to 30% and 27% of Ontario males and females.<sup>43</sup></li> <li>A Canada-wide Aboriginal peoples survey reported high rates of smoking (60%) in on-reserve FN.<sup>43</sup></li> </ul>	<ul style="list-style-type: none"> <li>Māori New Zealanders are more than twice as likely to be smokers than European New Zealanders (47.6%/ 39.5% respectively for Māori female and male compared to 19.5%/ 22.6% respectively for Caucasian males and females).<sup>65</sup></li> </ul>	<ul style="list-style-type: none"> <li>Smoking prevalence among persons aged 18 years was higher among AI/AN persons overall than among Non Hispanic White peoples, with the highest prevalence among AI/AN populations in Alaska and the Northern Plains.<sup>19</sup></li> </ul>
<b>Obesity and sedentary life-style</b>			
<ul style="list-style-type: none"> <li>Indigenous women were around one-and-a-half times as likely as non-Indigenous women to be overweight/obese.<sup>12</sup></li> <li>There was little variation in the rates of overweight/obesity for Indigenous and non-Indigenous men.<sup>12</sup></li> <li>Indigenous Australians were more likely than non-Indigenous Australians to be sedentary or to exercise at low levels.<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>High levels of obesity, a surrogate for higher calorie intake and reduced activity have been found among FN people.<sup>43</sup></li> <li>A study in Bella Coola Valley, BC found that 65% of Aboriginal people compared with 47% of non-Aboriginal people were overweight.<sup>72</sup></li> </ul>	<ul style="list-style-type: none"> <li>Māoris are 50% more likely to be obese.<sup>65</sup></li> <li>Māoris had a greater intake of red meat, saturated fat, and alcohol.<sup>65</sup></li> <li>Māori and non-Māori adults had a similar prevalence of overweight, but Maori adults were one-and-a-half times more likely to be obese than non-Māori.<sup>73</sup></li> <li>Māori and non-Māori adults were just as likely to be physically active.<sup>73</sup></li> </ul>	<ul style="list-style-type: none"> <li>In all regions, more AI/AN than Non Hispanic White men and women aged 20 years reported being obese, and reported no leisure time physical activity.<sup>19</sup></li> <li>One study found that almost half of AI/AN people over age 45 are overweight or obese.<sup>6</sup></li> </ul>
<b>Alcohol abuse</b>			
<ul style="list-style-type: none"> <li>In 2004-05, Indigenous people aged 18 years and over were more likely than non-Indigenous people to abstain from drinking alcohol.<sup>12</sup></li> <li>Of those who consumed alcohol, one in six Indigenous adults (16%) reported being long-term (or chronic) risky/high risk alcohol consumption.<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>The incidence of alcohol, drug and solvent abuse appears to be much higher in some Aboriginal communities, especially among Aboriginal youth.<sup>74</sup></li> <li>The Aboriginal Peoples Survey (based on self-report) showed that a lower proportion of Aboriginal people than Canadians generally drink weekly (35% Aboriginal versus 46% other Canadians). Abstinence is almost twice as common among Aboriginal people (15% Aboriginal versus 8% Canadian), but among those who consume alcohol, heavy drinking was more common.<sup>50</sup></li> </ul>	<ul style="list-style-type: none"> <li>Māori adults were less likely to have consumed alcohol in the past year than non-Māori adults. Maori males were more than one-and-a-half times more likely not to have drunk alcohol than non-Māori males (RR 1.6, CI 1.2–2.0). Among drinkers, Māori adults were more likely to have potentially hazardous drinking patterns which was one-and-a-half times higher for Māori compared with non-Maori adults (RR 1.5, CI 1.3–1.7).<sup>73</sup></li> </ul>	<ul style="list-style-type: none"> <li>One report showed that 60.8% of AI/ANs and 65.8% of other racial groups used alcohol in 2006, while 10.7% of AI/ANs reported having alcohol use disorder compared with 7.6% of other racial groups.<sup>75</sup></li> <li>Alcohol abuse is one of the top health problems among some AI Nations and communities, especially among young people.<sup>6</sup></li> <li>Variations found in the proportion of alcohol consumption from a low of 30% to a high of 84% in AI/AN communities; whereas the rate for the general population was 67%.<sup>76</sup></li> </ul>
<b>Chronic Hepatitis B Virus (HBV) Infection</b>			
<ul style="list-style-type: none"> <li>A higher prevalence of hepatitis B virus (HBV) infection has been shown in the Indigenous community than in the general population.<sup>77</sup></li> <li>Chronic HBV infection for Australians overall was estimated as ranging from 0.47% to 0.87%, whereas the prevalence in Indigenous Australians was estimated to be around 2% in urban areas and 8% in rural areas.<sup>78</sup></li> </ul>	<ul style="list-style-type: none"> <li>Prevalence of hepatitis B surface antigen has been reported to be high in the Inuit (6.9%); intermediate among FN(0.3%), and low in the general population.<sup>79</sup></li> <li>Some community-based studies found higher evidence of previous HBV exposure in Aboriginal communities in Canada.<sup>47</sup></li> </ul>	<ul style="list-style-type: none"> <li>Previous studies showed high rates of HB exposure and chronic HBV in Māori, ranging from 5.4% in Māori police and customs workers in the late 1980s to around 16% in Māori children in the Eastern Bay of Plenty in the early 1980s (prior to universal infant HBV immunisation).<sup>48</sup></li> <li>Significant regional variations found in the prevalence of HBV among Māori.<sup>48</sup></li> </ul>	<ul style="list-style-type: none"> <li>In the early 1980s, Alaska Natives had the highest rate of chronic HBV infection (&gt;13%) among all racial/ethnic groups of the US. The frequency of new HBV infections declined among ANs following a the immunization program begun in 1982.<sup>46</sup></li> <li>Alaska Natives have very high rates of chronic HBV infection and HBV-related hepatocellular carcinoma.<sup>44</sup></li> </ul>

**Table 2: Cancer risk-factors data for Indigenous populations across Australia, Canada, New Zealand and the US.**

Australia	Canada	New Zealand	US
<b>Area of Residence</b>			
<ul style="list-style-type: none"> <li>• A study from NSW found that cancer survival varied by remoteness of residence, with people living in remote areas being about 35% more likely to die from their cancer compared to people living in areas with the greatest access to services.<sup>80</sup></li> <li>• Aboriginal women living in rural areas have around nine times the risk of death from cervical cancer compared with non-Aboriginal women.<sup>81</sup></li> </ul>		<ul style="list-style-type: none"> <li>• No evidence found so far in New Zealand that people living further from a GP or from a cancer centre were diagnosed at a later stage in the disease than those living closer.<sup>41</sup></li> </ul>	<ul style="list-style-type: none"> <li>• One study showed that people living in rural parts of southern US have more advanced cancers at diagnosis than people living in urban areas.<sup>41</sup></li> </ul>
<b>Participation in breast screening</b>			
<ul style="list-style-type: none"> <li>• In 2004-2005, the age-standardised participation rates for Indigenous women aged 50-69 years (35.8%) was much lower than the non-Indigenous rates (55.9%).<sup>52</sup></li> </ul>		<ul style="list-style-type: none"> <li>• 41% Māori, 42% Pacific and 62% other women in the 50-64 years of age group over the period 2004-2006 reported to be accessed breast screening in NZ.<sup>82</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Mammography screening was lower among AI/AN women than among Non Hispanic Women but varied widely across Indian Health Service regions.<sup>19</sup></li> </ul>
<b>Participation in cervical screening</b>			
<ul style="list-style-type: none"> <li>• Pap test coverage for Indigenous women is lower than the total Australian coverage rate [27%-63% (reported individual health services or communities), compared with a national coverage reported for 1996/1997 of 62% of women aged 20-69 years].<sup>17</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Uptake of Pap test screening by Aboriginal women has been lower than that of by the general population.<sup>23</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Māoris are among those least likely to have a pap smear test.<sup>83</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Pap testing prevalence was the lowest in AI/AN populations with considerable regional variations in the uptake.<sup>19</sup></li> </ul>

Primary liver cancer can occur at higher rates due to the higher prevalence of chronic viral hepatitis infection and alcohol misuse. Breast, prostate, colorectal and pancreatic, cancers which were thought to occur less commonly among these populations are increasing. This increase could either be genuine or because of improvements in disease reporting and ascertainment of Indigenous status in these countries. The literature consistently shows a poorer outcome for Indigenous people with cancer across all four countries, attributed to late diagnosis, less compliance and discontinuing of treatment.

Relatively little attention has been given to exploring Indigenous views, perspectives, understanding and experiences with regard to cancer and cancer services in Australia, Canada, US and New Zealand. This review reveals different views on cancer among Indigenous populations across these four countries. The belief system comes from multiple factors, such as shared family values, relationship within the family and the community, environment, past experiences and cultural identity. This total worldview for Indigenous people is about wholeness and "a harmony within the physical and metaphysical worlds."<sup>57,59</sup> Such totality guides their values, beliefs and understanding of reality, which influences their behaviour. It has been consistently demonstrated that "individuals and groups use their basic beliefs to guide their actions."<sup>59</sup>

Although some similarities in the beliefs about cancer have been observed from published studies, further community-based research is needed to better understand Indigenous perspectives and needs and the way that these effect care-seeking behaviour. Furthermore, how and whether community beliefs differ between

urban, rural and remote populations has not been explored yet. This could impact the need for specific interventions to address such differences. Other than the research of Burhansstipanov and colleagues<sup>6,7</sup> in the US, few articles have reported the voices of Indigenous participants, with most information deriving from health service providers based upon their own interpretation of the Indigenous community. We conclude that there exists a need to better engage Indigenous people and to ensure that their own voices and stories are heard and represented in efforts to develop cancer-related services. Other countries have begun this process of better meeting the needs of Indigenous people<sup>7,24,25,39,42</sup> and Australia could learn much from their approaches. Without efforts to understand and willingness to make changes to accommodate the different perspectives of Indigenous people within the system of health care, the health care system with its focus on biomedical treatments is likely to fail to encourage many Indigenous clients.

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**Table 3: Beliefs about cancer of the Indigenous peoples of Australia, Canada, New Zealand and the US based on published studies.****1. Cancer means death**

- “When I hear the word, I feel fear. It is the big C you know, frightening, it means you’re going to die” [Australia]<sup>8</sup>
- “frightened, frightened. Cancer bad, make people die quickly.” [Australia]<sup>15</sup>
- “I’d kill myself if I got cancer, I couldn’t have all that pain and suffering.” [Australia]<sup>8</sup>
- “No one ever lived after cancer, they just went away to die.” [Canada]<sup>39</sup>

**2. Cancer is a “White man’s disease”**

- “It wasn’t here before the ‘Whiteman’. In the old days we were healthy, never had any problems. We eat bush food, possum, kangaroo meats, bush berries all that. We didn’t know about cancer, didn’t know what it was. No one had it...” [Australia]<sup>8</sup>
- “I tried to act White when I was young and that is why the Creator gave me a ‘White man’s disease’.” [USA]<sup>7</sup>
- “Cancer did not exist until White men brought the disease with them from Europe.” [US]<sup>7</sup>
- “Cancer was introduced to the Aboriginal community by Western society.” [Canada]<sup>39</sup>

**3. Punishment/curse/payback**

- “I got cancer because my son drinks and beats his wife and so that is why I have cancer, as a punishment of his bad behaviour.” [USA]<sup>7</sup>
- “I didn’t think I had acted badly, but I must have because now I have cancer.” [US]<sup>7</sup>
- “Aboriginal cancer these days, Aboriginal people they think different way. Frightened someone put that cancer in their body – someone trying to curse them. [Australia]<sup>15</sup>
- “I got cancer from my cousin.... She put a curse on me.” [US]<sup>7</sup>
- “My cancer was caused because I urinated on a spider. I didn’t see him, but it made him angry and he gave me cancer.” [US]<sup>7</sup>

**4. Cancer is contagious**

- “I got cancer because my daughter played with the daughter of ... who has the cancer spirit. So it is her fault that I have cancer.” [US]<sup>7</sup>
- “I caught my disease from that machine [mammography machine]. I didn’t have it before that machine touched me. Now I got it.” [US]<sup>7</sup>
- “A lot are frightened that they might catch it too, yeah.” [Australia]<sup>15</sup>
- “Surgery exacerbates cancer by exposing the cancer tumors to air”. [Canada]<sup>39</sup>

**5. People’s minds, feelings and perceptions have power to fight cancer**

- “A lot of cancers can be beaten; cancer comes when we do not look after ourselves.” [Canada]<sup>39</sup>
- “Every time a doctor tell you [that] you have cancer, s/her is shooting holes in your spirit. Each provider you see tells you about your stage or prognosis; that is another hole in your spirit. You have to heal all of those holes in your spirit to recover. You can’t just heal your body. You have to also heal your spirit.” [US]<sup>7</sup>

**6. Predetermined/Destiny/Fatalism**

- “Before I was born, my spirit selected cancer for me to learn some lessons... things that are important for me or my family to learn.” [US]<sup>7</sup>
- “Cancer is not a bad thing... it is just part of my path and my lessons. It is not upsetting. It has helped me greatly.” [US]<sup>7</sup>
- “My cancer diagnosis was a blessing... not an easy or pleasant blessing, but now, looking back, it was the best thing that happened to me.... I stopped drinking, I live a good life, I am in good health, and I appreciate every day the Creator has given me and my wife. My life is full of living, laughing, and loving ... because of cancer.” [US]<sup>7</sup>
- “Life will unfold in the way it was meant to be.” [Canada]<sup>39</sup>
- “What can be done about it (cancer)? It can’t be cured, can it? No one can stop it.” [Australia]<sup>8</sup>
- “I don’t really like talking about it because it makes me feel sad” and “talking could make it happen, tempt fate.” [Australia]<sup>8</sup>

**7. Cancer is not a priority here**

- “I have been here 9 months, worked here 5 years (with Indigenous people) and the cancer numbers are small.” [Australia]<sup>15</sup>
- “Natives don’t develop cancer.” [US]<sup>6</sup>
- “American Indians have a natural immunity for cancer.” [US]<sup>6</sup>
- “Cancer is rare among Aboriginal people.” [Canada]<sup>39</sup>
- “Aboriginal people have a natural immunity for cancer.” [Canada]<sup>39</sup>

**8. Bodies are sacred**

- “Our body is a creation of God that should not be interfered with no matter what happens.” [Australia]<sup>8</sup>
- “We have to respect God’s work. Our bodies are sacred.” [Australia]<sup>8</sup>
- “Maori and Pacific women are alike in that they see breasts and genitals area of the body as sacred, an area for their husbands only.” [New Zealand]<sup>83</sup>
- “I’m not happy to allow doctors to look down there. And because it’s hard to tell who’s gay and who’s not. I don’t want to be touched by someone like that.” [New Zealand]<sup>83</sup>
- “From our traditional understanding, our body is such a special thing that it is given everything it needs to heal itself. Similarly, we are given things in the natural world which are medicines.” [Canada]<sup>39</sup>

Note: \*Only themes identified in at a Level I qualitative research study and in more than one country are included.

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**CHAPTER FIVE**  
**Methodology**

## 5.1 Conceptual framework and study design

### 5.1.1 Choosing the study design

The impact of colonisation and disadvantages stemming from postcolonial government policies and programmes results in profound health disparities between Aboriginal and non-Aboriginal Australians in this country. The history of colonialism and its aftermath isolates Aboriginal communities from the mainstream society. Children were taken away from their families and placed in to missions where they were abused in many different ways. Assimilation policies significantly impacted on Aboriginal identity and extensive distrust developed among them towards non-Aboriginal system and authorities (Collard 2000; Dudgeon 2000; Garvey 2000). This unique experience has distinguished Aboriginal people from other minority communities in Australia. Throughout several decades Aboriginal people have been extensively researched without acknowledging their history, culture and ownership of knowledge and even sometimes, abandoning the people researched (Smith 1999). As a result of this, many Aboriginal people hold negative views about research – research has become a dirty word to Aboriginal communities. Research, for Aboriginal people, is linked to colonisation, oppression [11] and the exercise of power and control by the mainstream researchers. As Linda Tuhiwai Smith (1999) states,

*..., 'research' is probably one of the dirtiest words in the Indigenous world's vocabulary. When mentioned in many Indigenous contexts, it stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful. (1999, p. 1)*

To minimise the negative effect, scholars involved in Indigenous research have taken steps to make the research processes decolonised, ethical, responsible, accountable to and participatory for Indigenous peoples. There are now attempts to centralise Indigenous concerns, worldviews and perceived needs within research, to know and understand theory and research from their perspectives, and to better utilise the findings for their own benefit. This whole process is described as 'decolonisation' by Tuhiwai Smith (Smith 1999). Researchers start research with Aboriginal people within this context where they are required to be cautious about their positions, methods, relationships with the participants, accountability towards the participants and the community and the process of decolonisation.

This study addressed one of the under-researched areas and aimed to explore how Aboriginal people with cancer construct the meaning of their illness within their social context, experience their life circumstances and deal with cancer services. Social, cultural and political factors that influence their decision-making around access to health services were also identified. More work has been undertaken by other researchers and reported during the course of this study (McGrath et al. 2006; Prior 2006; Prior 2009; Walker et al. 2008).

Any health issue is more than just a health problem for Aboriginal people and is inextricably intertwined with a life situation that is influenced by the many crises Aboriginal people face. For instance, continuous loss of family and friends within their kinship relations, ongoing problems within the community; fear of dependence on the system, loss of functional abilities to perform their social roles and limited financial resources. This complex scenario is the “lifeworld” or lived reality (van Manen 1998) which is linked with the socio-political and cultural context and determines how Aboriginal people understand and interpret lived experiences or the meaning of an illness (van Manen 1998; Thome et al. 2004). It has become a widely accepted view that patients diagnosed with a similar illness may experience it fundamentally in many different ways (van Manen 1998). The formation of the study was also guided by this theoretical stance which aimed to understand meaning and lived experiences of cancer from Aboriginal perspectives, from the way they experience the situation. It was deliberately decided to focus on “cancer” generally rather than a specific type of cancer, to include men and women, and to seek information from people from urban, rural and remote areas. Wide variation was expected in their perspectives. The study used qualitative methods and was informed by the hermeneutic phenomenological research design as described by Max van Manen (1990). A philosophical discussion on phenomenology followed by some key principles and concepts important to understand this approach is provided below.

### **5.1.2 Phenomenology and associated concepts**

Phenomenology is a philosophical method that grew out of a chaotic context when European capitalism and its associated enlightenment ideologies were in crisis as a

result of the World Wars and their aftermath. Empiricism and rationalism (basic principles of positivism) that were considered as the basis of European capitalism and the social order were increasingly challenged by an indefensible subjectivism. Relativism was replacing many of previous ideologies and was hard to resist (Barnacle 2001) [Eagleton as cited in (Groenwald 2004)]. Disenchantment increased among scholars about the appropriateness of using quantitative or empirical methods in the field of human science. During the early 1980s, interest increased among scholars about the focus of inquiry that emphasized discovery, description, interpretation and self-reflection or critical analysis rather than detached observation, prediction, controlled experiment and quantitative measurement (Lavery 2003; Osborne 1994; van Manen 1990). William Dilthey (1976) said, “We explain nature, but human life we must understand” (van Manen 1990). Van Manen asserts that,

*... natural science studies ‘objects of nature’, ‘things’, ‘natural events’, and ‘the way that objects behave’. Human science, in contrast, studies ‘persons’, or beings that have ‘consciousness’ and that ‘act purposefully’ in and on the world by creating objects of ‘meaning’ that are ‘expressions’ of how human beings exist in the world..... Whereas natural science tends to taxonomize natural phenomena (such as in biology) and causally or probabilistically explain the behaviour of things (such as in physics), human science aims at explicating the meaning of human phenomena and at understanding the lived structure of meanings (van Manen 1990), p. 3-4.*

Phenomenology developed within this context. Edmund Husserl (1859-1938) is recognised as the father of phenomenological methodology. Although he started with a focus on mathematics, Husserl’s interests shifted over time as he perceived phenomenology as simultaneously objective and subjective, with subjectivity ultimately dominating his works (Reeder 1987). Husserl wanted phenomenology to offer a solid basis for all human knowledge, including scientific knowledge. He shifted the focus of the previous domain of knowledge that was concerned only with epistemological certainty [“absolute certainty of particular knowledge claims” (Barnacle 2001), p.4]. Husserl’s idea was formulated on the epistemological stance that knowledge cannot be objectified in its entirety as there will always be a relationship between the subject (the researcher) and object. Phenomenology, according to Husserl, is principally concerned with the systematic reflection on and analysis of the phenomena which appear in acts of consciousness. The Husserlian

school regarded knowledge or understanding as perspectival, and concluded that we never understand objects as a whole or as they actually are, but only certain aspects of them (Barnacle 2001), p.6. We can only be certain about how things appear in, or present themselves to, our consciousness (Groenwald 2004). ‘Consciousness’ was the key element in Husserl’s phenomenology. Valle et al. (1989) reported that Husserl viewed consciousness as a co-constituted dialogue between a person and the world (Lavery 2003).

Husserl introduced several concepts that have remained central to phenomenological analysis. One such element key to the understanding of phenomenology is the principle of “intentionality”. Intentionality means “directedness toward an object... the object may be either real or imaginary” (Lavery 2003), p.5. As van Manen frames the concept,

*From a phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human beings. And since to know the world is profoundly to be in the world in a certain way, the act of researching – questioning – theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to become the world. Phenomenology calls this inseparable connection to the world the principle of “intentionality” (van Manen 1990), p.5.*

Another important concept is the “essence”. Phenomenology attempts to reveal, understand and describe the internal meanings structures of a lived experience. Researchers engaged in phenomenological research aim to describe the phenomenon of interest as accurately as possible, refraining from using any pre-conceived framework (Groenwald 2004). The ‘essence’ is that universal structure that makes the study object or experience identifiable and unique from others. According to van Manen,

*A universal or essence may only be intuited or grasped through a study of the particulars or instances as they are encountered in lived experience (van Manen 1990), p.10.*



The essence can only be then achieved if the description of the lived experience encompasses the lived quality and significance of the experience in a fuller or deeper manner (van Manen 1990).

One of the biggest issues for phenomenological inquiry is that researchers' pre-understandings, suppositions, assumptions and the existing bodies of scientific knowledge influence them to interpret the nature of the phenomenon before they have even come to grasp with the significance of the phenomenological question. Husserl used the term "bracketing" to describe how one must control the phenomenon "and then place one's own knowledge about the phenomenon outside of it" (Husserl as cited in (van Manen 1990), p.47). Husserl described this as a three-fold process that includes exemplary intuition, imaginative variation and synthesis. In the first phase, researchers choose a phenomenon and hold it in imagination. Then they take that instance as a model and move to develop examples of similar experiences through imaginative variation, and in the final step, they integrate the variations of those experiences and grasp the essence (Klein and Westcott 1994). van Manen (1990) described bracketing as identifying one's presuppositions about the nature of the phenomena and then attempt to set them aside to see the phenomena as it really is. He added,

*If we simply try to forget or ignore what we already "know", we may find that the presuppositions persistently creep back into our reflections. It is better to make explicit our understandings, beliefs, biases, assumptions, presuppositions, and theories. We try to come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character (van Manen 1990), p. 47)*

Hans-Georg Gadamer, another student of Husserl, viewed bracketing as impossible and absurd. According to Gadamer (1976), understanding and interpretation in phenomenology are based on our historicity of being and will involve some prejudice. He did not believe that a researcher can leave his/her immediate situation in the present merely by adopting an attitude (Lavery 2003).

Although Husserl's conception of phenomenology has been criticised and developed by his students and by other existentialists and philosophers, his work is still considered central. Hermeneutic phenomenology is one branch of phenomenology which was developed by Martin Heidegger (1889-1976). While Husserl's focus was on understanding beings or phenomena, Heidegger was interested in 'the situated meaning of a human in the world'. Heidegger viewed humans as being principally concerned creatures who are concerned on their fate in an alien world. He argued, "The meaning of phenomenological description as a method lies in interpretation.... The phenomenology ... is a hermeneutic in the primordial significance of this word, where it designates this business of interpreting" (Heidegger, 1962 as cited in van Manen, 1990, p 25). Heidegger also added an important component in phenomenological analysis – the formation of historically lived experience. Heidegger emphasised the historicity of understanding as one's background or situatedness in the world. A person's history or background also includes their cultural orientation and influences their understanding of the world. Heidegger had a view of people and the world as indissolubly related in cultural, social and historical contexts (Munhall 1989). In this view, all understanding is connected to a given set of forestructures, including one's historicity and experiences. Thus, one needs to be aware of these interpretive influences. Polkinghorne (1983) described this interpretive process as concentrating on historical meanings of experience and their development and cumulative effects on individuals and social contexts (Lavery 2003). The basic difference between Husserl's transcendental method of descriptive phenomenology and hermeneutic phenomenology is that the former is a pure description of lived experience and the latter one concentrates on the interpretation of that experience via some "text" or symbolic form (van Manen 1990).

In summary, some of the basic characteristics of phenomenological research as van Manen (1990) listed are discussed below:

- Phenomenological research is the study of the lifeworld – the world as we experience it pre-reflectively. It does not aim to build effective abstract theory with which the world can be explained and controlled, but rather it provides reasonable insights on one's experience that help researchers in more direct contact with the world.

- Phenomenological research is the revelation of a phenomena or the object that can be real or imagined and empirically measurable or subjectively felt as they present themselves to our consciousness. This type of research is reflection on experience that is already passed or lived through.
- Phenomenological human science tries to describe and interpret lived experiences to a certain degree of depth and richness. “It differs from other disciplines in that it does not aim to explicate meanings specific to particular cultures (ethnography), to certain social groups (sociology), to historical periods (history), to mental types (psychology), or to an individual’s personal life history (biography)” (van Manen 1990), p.9.
- Phenomenological research is “a systematic, explicit, self-critical, and intersubjective study of its subject matter” [ref?]- the lived experience.
- “Phenomenological knowledge is empirical, based on experience, but it is not inductively empirically derived. This does not allow for empirical generalisations, the production of law-like statements, or the establishment of functional relationships. Generalisations about human experiences are almost always of troublesome value. Hence, the only generalisation applicable to phenomenology is that: Never generalise!” (van Manen 1990), p.21
- Phenomenological research takes account of lived experience or empirical data. So, it is not just ‘speculative inquiry’ in the sense of unworldly reflection
- Phenomenological research asks meaning questions. Phenomenologists do not seek to solve any problem but rather ask for the meaning and significance of certain phenomena According to van Manen (1990), “A phenomenologist might want to study concrete examples of real talk, the quality of the relation between people, the nature of the space which is somehow “good” for having a talk. A phenomenologist would not likely send around questionnaires, or place individuals in experimental situations to see under what controlled conditions real talk happens: and he or she would not simply start to “philosophize” about the nature of real talk either” (van Manen 1990), p.24 .

### **5.1.3 Philosophical assumptions and choice of methods**

It is crucial to explicitly clarify a researcher's philosophical positioning at the start of any research because it guides the researcher to decide how social phenomena need to be addressed and studied. The underlying principles of the social constructionist perspective guided the choice of research topic, framing of the research question of the study and the methodology. Social constructionist perspectives, in contrast to the positivistic stance, seek to understand how people interpret and make sense of phenomena within particular social and historical contexts. As Goulding puts it, "a person's life is a socially constructed totality in which experiences interrelate coherently and meaningfully" (Goulding 2005) p.23. As one of the two main epistemological stances, social constructionism underpins most of the recent developments of several alternative approaches, such as critical psychology, discourse analysis, deconstructionism, poststructuralism, critical feminist theory, social ecological theory and so on (Burr 1995). The approaches of Dilthey and Max Weber focused on interpretive understanding or Verstehen to access the meanings of participants' experiences as opposed to explaining or predicting their behaviour which was the goal of the empirico-analytical paradigm or quantitative research (Ajjawi and Higgs 2007). Empiricism, the basis of positivism, perceives reality as universal, objective and quantifiable, and argues that generalisation is attainable about a phenomenon as everyone shares the reality in the same way. Social constructionism, on the contrary, views the actors or objects as a sense maker of their context and experiences (Darlaston-Jones 2007). According to this paradigm, meanings are constructed by human beings and are influenced by their context and personal frames of reference as they connect with the world (Ajjawi and Higgs 2007).

To address the research question of understanding Aboriginal people's decision-making process about access to cancer-related services in WA, literature informed by the positivist paradigm would focus on the role of Aboriginal people in terms of their motivation, self-responsibility, awareness and education, ability and social epidemiology. This perspective aligns with the concept of 'victim blaming' (Germov 2005) and does not consider the context within which Aboriginal people act. The social constructionist paradigm focus on the reality of each person having complex

decision-making processes that are influenced by an individual worldview shaped by their surroundings, culture, social, economic status, historical or prior experiences. As a researcher, it is virtually impossible to objectively scrutinise another person's subjective experiences yet we can only interpret other peoples' actions using our own understanding of what we think their world is like (Darlaston-Jones 2007). A pattern of meaning (Creswell 2007) about meaning of cancer and possible factors influencing Aboriginal peoples' decision-making processes was inductively derived from the study. This worldview informed the formation of the study, and guided to decide different parameters/ methods of investigation.

According to Creswell, researchers exploring the meaning of a subjective and first-person experience (Smith 1999) may adopt the phenomenological perspective as this approach allows the researcher to understand a phenomenon at a deeper level through unveiling the "life experiences" of several individuals. The approach also reports descriptions and interpretive "meanings" consisting of "what" individuals experienced and "how" they experienced it (Creswell 2007). This approach is ideal for investigating personal journeys and pre-reflective experiences and feelings about a phenomenon. A key aspect of this research was to explore Aboriginal Australians' understanding of cancer and their experiences with cancer and cancer services in WA. The use of hermeneutic phenomenology added the component – 'interpretation' and enabled the exploration of participants' experiences by further considering their historicity and cultural and social background. Thus, in this study, two key concepts – 'meanings of cancer' and 'experiences with cancer and cancer services' were explored from the lived experiences of Aboriginal Australians.

Phenomenology was considered suitable for this research because it emphasises the meaning of experiences for a number of individuals. Grounded theory approach was not adopted because the intention was not to generate or discover a theory. Grounded theory goes beyond description and aims to generate an abstract analytical schema of a process or a theory (Creswell 2007). Phenomenology does not aim to develop abstract theories (van Manen 1990). The aim of this study was to understand Aboriginal Australians' meaning of cancer and their experiences with cancer services

in a descriptive manner. Attempts were made to interpret and understand such experiences by considering diverse factors that can affect their experience. The study was neither designed to be conducted in a particular area, nor was it planned to be done with a particular Aboriginal community. Hence, ethnography was not adopted. Moreover participant observation, one of the key methods of data collection of ethnography, was not considered suitable for this particular research.

Phenomenology does not impose a structure in undertaking a study in advance. Rather the phenomenon of interest is apprehended and explored as it is viewed and experienced by people involved with it. In Barnacle's views, "when we attempt to understand the world we do not access it 'as it is' but rather 'as it is to us' – and indeed in trying to make sense of the world it is inevitable that we will always find something of ourselves, both historically and culturally." (p.7) Understanding occurs in relation between thought and its object, rather than in the application of principles or propositions decided in advance of that relation. Thought is relational.

The interpretation and analysis of findings was guided by the social ecological framework, which is an overarching interpretive framework that examines and assists understanding the intertwined relationships among diverse personal and environmental factors to explain a phenomenon (Stokols 1996). This approach is well suited to Aboriginal health research because it aligns with Indigenous holistic values and considers physical, mental, emotional and spiritual aspects of healing and wellness together for the total well-being of an individual (Aboriginal Cancer Care Unit 2002, 2002). Understanding Aboriginal care-seeking behaviour and health consequences is too complex to be understood adequately from a single level of analysis, and requires more comprehensive approaches that recognise and integrate psychological, organisational, cultural, structural and broader socio-economic and political (Stokols 1996). The interpretive paradigm was favoured because of its potential to generate new understandings of complex multidimensional human phenomena, as in this research which studied beliefs, understanding and experience.

#### 5.1.4 Data collection and analysis

Multiple sources, including observations, document analysis and one-on-one in-depth interviews with individuals were used to collect data. Thirty in-depth interviews were carried out with Aboriginal cancer patients, survivors and family members who had close experience of cancer in their families from several sites in WA. Site-selection was based on the cancer prevalence areas in WA. Rural and remote sites were selected based on the established relationship of the supervisor with several Aboriginal communities in WA. In addition, 20 health service providers from a variety of service settings were interviewed, although these interviews are not analysed or reported in this thesis.

A purposive sampling strategy was used during recruitment although a small number of participants were recruited through snowball sampling in rural areas in the later phase of the study. Purposive sampling was chosen because it is being considered as the most effective non-probability sampling technique to identify key informants [Welman and Kruger, 1999 as cited in (Groenwald 2004)]. Research question of the study also guided the selection process as I was looking for participants who got the most relevant experiences in relation to the phenomenon of interest. Snowballing, the technique which asks participants to suggest others for interviewing, was used to expand recruitment. I requested some purposive sample interviewees and the ARG members to refer me to a person who had been living with cancer themselves or had experience in dealing with cancer within their family.

At the end of most interviews, I documented my overall impression and reflections on the interview. These reflections were then documented as a memo<sup>3</sup> (dates were included) within NVivo so that feeling and ideas that arose about the research were captured. ‘Memoing’ (Birks, Chapman, and Francis 2008) is an important information source where “the researcher’s field notes recording what the researcher

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<sup>3</sup> Memo is an abbreviation (and common usage) for memorandum (which has a much more formal usage). Memos, in the context of data analysis, are used to capture thought and insights we have when we work through the data. The computerized equivalent of a notebook, they are great tools for noting down possible themes, ideas and concepts that we want to go back and explore later. (QSR International, NVivo 7 Workbook, 2006-2008, p 17)

hears, sees, experiences and thinks in the course of collecting and reflecting on the process”(Groenwald 2004), p.13. These reflections were linked with the responses during data analysis, and often helped interpreting and understanding the participants’ context, experiences and responses. My impressions, observations, any significant incidents and reflections upon limitations and negative events on the overall research process were recorded in a separate reflective journal. The reflective journal supports the credibility, transferability, dependability and confirmability of a study (Erlandson et al. 1993). According to Lincoln and Guba (1985), a reflective journal is a kind of diary in which the investigator on a regular basis records information about him or herself and their impressions while conducting research. They have suggested a daily journal (Lincoln and Guba, 1985). The reflective journal also provided an opportunity to ‘bracket’ my own feelings, opinions, preconceptions and biases towards the research topic, process, participants and data. I documented what I knew about Aboriginal people before I started this research, what I heard about them, how my conceptions and understanding was shifting and changing, how my collective experience of colonisation impacted/ assisted my understanding of the Aboriginal context and so on. I was constantly deconstructing my perspective throughout this research and reflective journaling, although quite erratic, helped the process.

Initially, the existing literature in regard to cancer beliefs, service strategies and treatment experiences among Indigenous populations both in Australia and in other parts of the world were examined to identify the categories, processes, problems and common themes within the literature. This analysis guided the design of the qualitative research approach and the instruments (a theme list) for the study, as well as the conduct of qualitative data collection and analysis in the subsequent phases of the research. The theme list has been included in the methodology paper from the research (Shahid, Bessarab et al. 2009).

After each interview, I listened to the audio recording once or twice to become familiar with the words and context. I was also comparing my field notes with the tape recording and documenting any new interpretation and understanding coming



through the process. Responses from participants were then transcribed verbatim from the tape recordings, and the manuscripts were reviewed several times. This was done by reading the transcription line-by-line and paragraph-by-paragraph (Chenitz and Swanson 1986). Initially notes and comments were written on the manuscripts of the interviews to identify the patterns in the respondents' thoughts and ideas. Transcripts were independently coded by at least one of Kim Worthington, Lisabeth Finn or Sandra Thompson, and differences discussed and resolved within the group of coders. Group coding of this type helped to enhance the validity and dependability of the data analysis and interpretation (Lincoln and Guba 1985). All of those coded texts were then ordered, recorded and stored using the Qualitative Data Management Software NVivo7. I should clarify here that computer software does not analyse, interpret and understand the meaning of phenomena; rather it can ease the hard and time-consuming task of "analysing text-based data through rapid and sophisticated searches, line-by-line coding, and so on" (Groenwald 2004), p.20. The initial findings or the essence (Groenwald 2004) of each interview were brought back to the participants where possible for corrections and validation. It was not possible to go back to all participants in rural and remote areas due to funding and other personal constraints.

The next stage of data analysis was the formation of categories. Information contained under similar content was grouped to form preliminary categories (Lincoln and Guba 1985). We also noted how many times a meaning was mentioned and how it was stated. The frequency and distribution of important codes were identified, highlighted and grouped. Following identification of the categories, themes were recognised at the final stage of the analysis. Noteworthy topics or units of significance (Sadala and Adorno 2001) were identified in consultation with my supervisor and other people involved in coding. Overlap often occurred within the clusters of meaning. We discussed, interrogated and determined core themes. Priority was given to use quotes and themes in words of participants in published findings, thus the minority voices were not ignored.

Detailed description of the study design, approaches, data collection methods and analysis is provided in the paper “Exploration of the beliefs and experiences of Aboriginal people with cancer in Western Australia: A methodology to acknowledge cultural difference and build understanding” included in Chapter 4.

This paragraph will talk about how trustworthiness was attained as part of this qualitative research study. To ensure quality of qualitative research Lincoln and Guba (1985) suggest the importance of ‘trustworthiness’, instead of ‘reliability’ and ‘validity’ that are most commonly used in quantitative research.. According to them ‘trustworthiness’ will ensure the researcher as well as the audience can reliably depend on the findings from an inquiry. “How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of?”(Lincoln and Guba 1985), p.290. Trustworthiness can be attained in qualitative research when credibility (similar to internal validity), transferability (resembling external validity), dependability (similar to reliability) and confirmability (akin to objectivity) (Lincoln and Guba 1985; Westphal 2000) are ensured.

To ensure credibility, time was spent to make relationships and build trust with the participants and relevant communities. Efforts were made to ensure participants understood and were informed about the study while exercising caution not to impose meaning. I conducted all the interviews, and in some instances was assisted by an Aboriginal navigator who was familiar with the context. This was decided in consultation with the participants. To reinforce dependability, analyses were performed concurrently with the data collection process and initial themes were brought back to some informants for verification. I worked closely with the Aboriginal Reference Group (ARG) during the whole process of this research. Dependability was also achieved by using a triangulation process in the analysis, where the findings were discussed by my supervisor, other associates and I, each of us bringing different degrees of proximity to the interviews and context. Field notes were maintained in detail. Direct quotations were used in reporting the findings from the study. This provides real examples of the understandings, thoughts, feelings and

experiences of the people interviewed. Transferability could have been strengthened if some form of conformity could be maintained, for example, if I could focus on same type and stages of cancer or persons of similar backgrounds could be recruited. However, when the study began there was no precise information available on different types of cancers diagnosed among Aboriginal people in WA. Although more work has been undertaken and reported during the course of this study (McGrath et al. 2006; Prior 2006; Prior 2009; Walker et al. 2008), little was known about how Aboriginal people with cancer experience and interpret the meaning of their illness when the study was conceptualised. Thus, I had to keep the focus quite broad. The findings may thus assist to develop a general understanding about Aboriginal people's meaning of living with cancer and then be applied to new comparable context.


To Whom It May Concern

I, Associate Professor Dawn Bessarab, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia.

I assisted Shaouli Shahid in the beginning of the data collection phase by giving her some advice around approaching and working with Aboriginal people. Additionally, I guided her in organising the main themes from the findings, and participated in writing the paper published as:

**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 Med Res Methodol. 2009 Aug 13;9: 60.**

The writing of this paper was led by Shaouli Shahid. I commented upon drafts of this paper and checked the final version of the article.



(Signature of Co-Author)

Associate Professor Dawn Bessarab



(Signature of Candidate)

Shaouli Shahid

To Whom It May Concern

I, Professor Peter Howat, was involved in the initial designing of the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia.

I actively participated in writing the paper published as:

**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 Med Res Methodol. 2009 Aug 13; 9: 60.**

The writing of this paper was led by Shaouli Shahid. I commented upon drafts of this paper, assisted with responses to reviewers and checked the final version of the article.



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(Signature of Co-Author)

Professor Peter Howat



(Signature of Candidate)

Shaouli Shahid

To Whom It May Concern

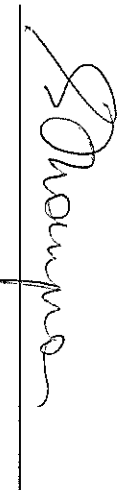
I, Professor Sandra Thompson, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia since it was started.

I coordinated the whole project, participated in the design and assisted with the conduct of the study. I actively participated in writing the paper published as:

**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 Med Res Methodol.**

**2009 Aug 13;9:60**

The writing of this paper was led by Shaouli Shahid. I commented upon drafts of this paper and approved the final version of the article.



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## Exploration of the beliefs and experiences of Aboriginal people with cancer in Western Australia: a methodology to acknowledge cultural difference and build understanding

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### Abstract

**Background:** Aboriginal Australians experience poorer outcomes, and are 2.5 times more likely to die from cancer than non-Aboriginal people, even after adjustment for stage of diagnosis, cancer treatment and comorbidities. They are also less likely to present early as a result of symptoms and to access treatment. Psycho-social factors affect Aboriginal people's willingness and ability to participate in cancer-related screening and treatment services, but little exploration of this has occurred within Australia to date. The current research adopted a phenomenological qualitative approach to understand and explore the lived experiences of Aboriginal Australians with cancer and their beliefs and understanding around this disease in Western Australia (WA). This paper details considerations in the design and process of conducting the research.

**Methods/Design:** The National Health and Medical Research Council (NHMRC) guidelines for ethical conduct of Aboriginal research were followed. Researchers acknowledged the past negative experiences of Aboriginal people with research and were keen to build trust and relationships prior to conducting research with them. Thirty in-depth interviews with Aboriginal people affected by cancer and twenty with health service providers were carried out in urban, rural and remote areas of WA. Interviews were audio-recorded, transcribed verbatim and coded independently by two researchers. NVivo7 software was used to assist data management and analysis. Participants' narratives were divided into broad categories to allow identification of key themes and discussed by the research team.

**Discussion and conclusion:** Key issues specific to Aboriginal research include the need for the research process to be relationship-based, respectful, culturally appropriate and inclusive of Aboriginal people. Researchers are accountable to both participants and the wider community for reporting their findings and for research translation so that the research outcomes benefit the Aboriginal community. There are a number of factors that influence whether the desired level of engagement can be achieved in practice. These include the level of resourcing for the project and the researchers' efforts to ensure dissemination and research translation; and the capacity of the Aboriginal community to engage with research given other demands upon their time.

### Conceptualising the study

The profound health disparities that arise out of political, social, economic, educational and other disadvantage experienced by Aboriginal and Torres Strait Islander (hereafter Aboriginal) people in postcolonial Australia are well described. In this paper, the term Aboriginal denotes Indigenous people of Australia. We have used "Indigenous" to refer to common features that are identified across different Indigenous peoples. As data collection systems have improved, it has also been recognised that Aboriginal Australians have a higher incidence of some preventable, especially smoking-related malignancies compared to non-Aboriginal Australians and are less likely to access cancer screening, more likely to be diagnosed at a more advanced stage and to have poor continuity of care and lower compliance with treatment[1]. Aboriginal cancer rates appear to be increasing and Aboriginal people experience lower survival for all cancers when adjusted for stage at diagnosis [1-3]. Further research that merely continues to describe these gaps is limited in its use.

In public health research, consideration should be given to both quantitative *and qualitative* research when planning health promotion interventions. Qualitative research is increasingly recognised as playing a role in understanding the determinants of health behaviour, and informing alternative approaches[4]. Qualitative research can also enable an appreciation of the socio-cultural and historical context in which the problems or risks are constructed[5] and provide information upon which specific interventions or changes in policy and practice can be based.

This research aimed to explore Western Australian (WA) Aboriginal perspectives and experiences of cancer, cancer services and treatment from the lived experience of Aboriginal people. The project was conceived to find out information which might assist the development of effective health promotion interventions in cancer control in the Aboriginal community.

This paper explores methodological considerations in conducting the research which was initiated by non-Aboriginal researchers in response to a need identified by service providers for greater understanding of Aboriginal beliefs about cancer[6].

### Key considerations and challenges in Indigenous research

Aboriginal and Torres Strait Islander people are the original inhabitants and the Indigenous people of Australia with a history of 60,000 years of habitation. Since the arrival of the first colonists in 1788 Aboriginal people's lives have changed dramatically. Devastating affects of colonization resound through the generations and is con-

sidered to be one of the underlying reasons impacting on the poor health of Aboriginal people today.

### Colonisation and decolonisation

It is imperative to understand the historical context of Aboriginal people in Australia when attempting to conduct research with Aboriginal communities and individuals. Part of the colonial legacy is the negative view that many Aboriginal people hold of research. This is a consequence of past unethical practices where research was inappropriately carried out *on* Aboriginal Australians rather than *with* them and was often undertaken without adequate consultation or informed consent[7,8]. Denzin and Lincoln (2008) have framed it this way – "Western scientists discovered, extracted, appropriated, commodified, and distributed knowledge about the Indigenous other[9]." All these experiences have contributed to research becoming a dirty word[10] to Indigenous communities with research linked to colonisation, oppression[11] and the exercise of power and control over Indigenous peoples. To minimize such consequences, scholars involved in Indigenous research have taken steps to make the research processes decolonized, ethical, responsible, accountable to and participatory for Indigenous peoples. There are now attempts to centralise Indigenous concerns, worldviews and perceived needs within research, to know and understand theory and research from their perspectives, and to better utilise the findings for their own benefit. This whole process is described as 'decolonisation' by Linda Tuhiwai Smith [10].

### Indigenous paradigm

In the last 20 years [12], there has been a paradigm shift in Australia and internationally when undertaking Indigenous research away from research which conceptualised and understood systems of knowledge in conventional positivistic social science terms. 'Indigenous scholars from Australia, Aotearoa-New Zealand, the United States, and Canada have brought to academic discussions the Indigenous peoples' project of reclaiming control over Indigenous ways of knowing and being'[11,13,14]. Indigenous methodological approaches are based on Indigenous epistemologies that privilege Indigenous voices and ways of knowing and understanding the social world. For Indigenous people, knowledge is relational and Indigenous knowledge systems are founded on relationships with other people, the land and everything around them. Indigenous epistemology recognizes that there is more than one reality and meaning in understanding the social world [15].

Whereas positivistic research is based on objectivity, qualitative research is subjective and undertakes to describe the social world through the lived experience of the participant. These two different research approaches lead to dis-



tinctly different research processes, design and methodology. The positivistic scientific research process requires researchers to remain outside the research experience, to investigate through observation and discovery, as objectively or neutrally as possible, and to draw conclusions based on those observations[11]. Indigenous research, on the other hand, develops a shared relationship between the researcher and the researched population who must be interconnected in a reciprocal way during the research process. Principles of respect, reciprocity and relationality are critical for Indigenous methodologies.

### **Practical challenges and stigmatisation towards Aboriginal community**

There can be difficulties in accessing Aboriginal people as research participants given that they are often marginalised, suspicious of research and of discussing personal experiences with strangers. In regional/remote areas, distance makes travel challenging and people difficult to access. Aboriginal people in communities often speak their own language as a first language with English being their second or third language. Cultural protocols and taboos must be followed when engaging with Aboriginal communities[7]; failure to do so can limit researchers' interaction with their Aboriginal participants and cause mistrust and misunderstanding. These factors may be some of the reasons behind the dearth of systematic investigation of what underlies poor Aboriginal cancer outcomes[1]. Apart from these access difficulties, negative stereotypes about Aboriginal Australians can influence non-Aboriginal people's attitudes and behaviours towards them[16] as it is unlikely that researchers are not influenced by stereotyping and the institutional and overt racism that exists in mainstream Australia.

### **Axiology (values and ethics) in conducting this research**

Indigenous axiology, which incorporates nature, types and criteria of values and value judgments, are of great importance in designing Indigenous methodologies; especially in relation to research ethics. Indigenous research ethics encourages researchers to incorporate alternative perspectives, and apply nuanced judgments to any ethical implications. Six values (see Table 1) outlined in the National Health and Medical Research Council (NHMRC) guidelines for ethical conduct of Aboriginal and Torres Strait Islander health research[17] in Australia, were followed for this particular study. Ethics approvals were obtained from the Human Research Ethics Committee (HREC) of Curtin University, the Western Australian Aboriginal Health Information and Ethics Committee, and the Royal Perth and Sir Charles Gairdner Hospitals. Approval was also obtained from local Aboriginal Health Services.

Another important consideration is the nature of 'insider' and 'outsider' positions of research conducted in Indigenous settings[10]. Because the research team was university educated, predominately non-Aboriginal and not local community members, the researchers were aware they would be considered 'outsiders'. They were cautious about their interpretation of different issues while collecting data as they understood that they might not have the intimate, intuitive understanding of the world of an 'insider'. To assist with overcoming this, a local trusted person was engaged to introduce the interviewer on each rural and remote visit; sometimes they remained throughout the interview. This process assisted fostering the development of a trusting relationship with the participants and assisted the researchers to maintain local cultural protocols. Aboriginal participants were assured that they need only provide information that they were comfortable with sharing. Standard research processes were adopted to ensure the confidentiality of individuals and the integrity of the data collected.

## **Research methodology**

### **Research design**

This research was considered exploratory since few studies have examined Aboriginal peoples' understanding, knowledge and beliefs about cancer and experiences of cancer care[1]. The diversity of the Aboriginal population in Australia, to which further differences have accumulated in terms of acculturation, education and opportunity, meant that considerable variation was expected between participants. Two key concepts – 'meanings of cancer' and 'experiences with cancer and cancer services' were explored from the lived experiences of individuals. The phenomenological qualitative approach was chosen because of its suitability for research that seeks to provide an insight into how people make sense of, describe and interpret their experiences and portray the process involved in a phenomenon. This methodology aims to extract "the contextualized nature of experience and action, and attempts to generate meaning that are detailed, 'thick', and integrative[18]."

The establishment of an Aboriginal Reference Group (ARG) at the beginning of the research was crucial to assist and ensure that all stages of the research adhered to and acknowledged community values and aspirations. Members of the ARG were acknowledged as professionals both by their Aboriginal and non-Aboriginal peers in the areas of Aboriginal health and welfare. Initially, researchers utilized their personal networks to identify Aboriginal people who were working in different cancer services and in other Aboriginal health services in WA. Researchers then approached them personally, explained the initial research plan, processes and the purpose of forming the ARG. Aboriginal people, who expressed interest, to the

**Table 1: The six key values that lie at the heart of research engagement with Aboriginal communities activities as recommended by the National Health and Medical Research Council and the activities undertaken to address those values while conducting this research.**

<p><b>i. Reciprocity</b>                  Reciprocity entails the inclusion and recognition of participants' contributions and in return the delivery of research outcomes that benefit the communities or individuals. The benefit should be valued by Aboriginal individuals and communities.</p>	<ul style="list-style-type: none"> <li>• Sharing of knowledge and expertise</li> <li>• Assistance give to ARG members with their personal and professional needs</li> <li>• Researchers assisted with writing applications to gain support for ARG members</li> <li>• Funding for reimbursing some organisations that provided assistance</li> <li>• Capacity building as part of the research, e.g. through co-presenting research findings and assisting develop an Indigenous cancer support group as an outcome of the research</li> </ul>
<p><b>ii Respect</b>                  Respect for individual and collective culture and acknowledgement of the right of Indigenous Australians to have different values, norms and aspirations are critical to the research process. This is fundamental to have a sustainable research relationship between participants and researchers.</p>	<ul style="list-style-type: none"> <li>• Consultation with and involvement of Aboriginal people throughout the research; guidance by ARG</li> <li>• Flexibility of the research design with modifications to reflect feedback</li> <li>• Acknowledgement of differing cultural beliefs and understanding of health and illness</li> <li>• Responsiveness to feedback and ensuring that some feedback of study results occurs to Aboriginal people</li> </ul>
<p><b>iii Equality</b>                  Equality affirms Aboriginal and Torres Strait Islander peoples' right to be different and thus entails the appreciation and respect towards these differences while performing research.</p>	<ul style="list-style-type: none"> <li>• Valuing of Aboriginal knowledge and wisdom through exploring Aboriginal perspectives, knowledge and preferences to inform the research process</li> <li>• Actively encouraging Aboriginal involvement and support</li> <li>• ARG's comments and suggestions on any aspect of the project valued</li> <li>• Aboriginal people are co-presenters and co-authors of findings</li> </ul>
<p><b>iv Responsibility</b>                  The recognition of "core responsibilities", including those to country, family, community and maintaining harmony between the spiritual and physical realms.</p>	<ul style="list-style-type: none"> <li>• Attention to minimizing risk and ensuring no harm to participants and no unintended consequences</li> <li>• Accountability to Aboriginal stakeholders</li> <li>• The research process included: adequate, transparent consultation, opportunities for feedback during the development and conduct of the research, distribution of research findings in a way that was accurately represented, appropriate and understandable</li> </ul>
<p><b>v. Survival and Protection</b>                  The need to protect Aboriginal cultures from erosion and maintain the collective identity.</p>	<ul style="list-style-type: none"> <li>• Reflected in the aim of the research to explore Aboriginal perspectives and the intent of reporting the findings in a way that is respectful of Aboriginal values and does not inadvertently contribute to discrimination or derision of Aboriginal Australians</li> </ul>
<p><b>vi Spirit and Integrity</b>                  It refers to show respect for the richness and diversity of Aboriginal and Torres Strait Islander peoples' cultural inheritance of past, present and future generations and of the links which bind the generations together and requires the behavioural and perceived integrity of the researchers.</p>	<ul style="list-style-type: none"> <li>• Recruitment strategy to capture a broad range of Aboriginal perspectives, enriching the diversity of knowledge obtained.</li> <li>• Flexibility around timeframes, recognition of the importance of relationships while conducting the research</li> </ul>

extent of being willing to commit their time were formally requested to be a part of the ARG. The management of data, the protection of individual and community identity and the dissemination of findings were discussed throughout with the ARG members.

**Development of an interview guide**

An open-ended, exploratory general theme list that could guide semi-structured interviews was initially developed. The guide was based upon an in-depth examination of common themes identified in the existing literature on cancer beliefs and understanding among the Indigenous population in Australia, Canada, New Zealand and the USA[1]. This literature guided the approach and the design of an appropriate qualitative research instrument,

the approach to data collection and the analysis in the subsequent phases of the research. The initial draft was modified after discussion with the ARG. The topic list is included in the Appendix.

**Participant recruitment and data collection**

Data collection occurred in two rural and one remote community and in the urban Perth metropolitan area. Thirty interviews were conducted among Aboriginal cancer patients, survivors and family members of people with cancer or who had died of cancer. Interviewees were male and female adults. Recruitment initially occurred through the networks of the researchers and reference group and also through health professionals in primary or tertiary care. Some limited snowball recruitment occurred as ini-

tial participants recommended others as candidates for the study, but care was taken to ensure a mix of males and females, types of cancer and geographical locations. Recruitment and data collection continued until the research team was satisfied the data was comprehensive and rich, and there was repetition of themes in the interviews with new participants[18].

Agreement for the research to occur was obtained from local community leaders and community health organisations in rural or remote regions. Whenever possible, participants were given an information statement about the research well before the interview which clearly explained its purpose, procedures, risks and benefits including the rights of the participant and contact information for the researcher. Participants were invited to have a support person present at the interview if they wished. Before beginning the research interview, time was spent building a relationship with the participant. Several strategies were used, for example, the interviewer visiting several times before the actual interview date, or sharing her personal stories and background to make the participant feel comfortable and to assist with establishing a relationship. The interviewer explained the research and obtained written consent before the formal interview commenced; agreement for the interview to be recorded was obtained separately. Interviews varied considerably in length, commonly lasting around 1.5 hours.

Once the relationship had been established and any initial anxiety was reduced, participants were asked to share the story of their journey with cancer (either their own or their family member). They were asked to include their experiences of diagnosis, treatment, recurrence of cancer and to suggest strategies to address the issues they faced during their cancer journey. They were also asked about their perspectives and meaning attached to cancer. A narrative method was chosen because the study aimed to explore the complexity and in-process nature of meanings and interpretations of Aboriginal men and women's experience of cancer. The interviews were akin to conversations, letting the interviewees talk freely and frankly about their cancer experience, and the meanings and understandings they attributed to it. This flexible style was chosen so that people's voices could be heard accurately and in their own way. Some interviewees reported they had not previously discussed their cancer experience and many found it quite liberating, even cathartic, to have the opportunity to reflect on and talk about it. The topic list was not generally needed to guide the interviews.

Information was also collected from relevant Aboriginal and non-Aboriginal health service providers from a mixture of primary and tertiary health care service settings. Their inclusion ensured triangulation of views on Aborig-

inal perceptions and engagement with cancer-related services. It also helped to recognise the nature of differences that Aboriginal people and health service providers had in understanding cancer and relevant services. Twenty providers were interviewed between March 2006 and September 2007.

In addition, a field log was carefully maintained throughout, documenting impressions, observations, any incidents, the research process, and reflections upon limitations and negative events. These reflections were linked with the responses during data analysis.

#### **Data analysis**

All interviews were audio-recorded and transcribed verbatim. Initially, manual open coding[19] was carried out independently by two researchers who carefully read and re-read hard copies of the transcript. Differences were later discussed and resolved in the research team[20]. Detailed coded texts were entered into N-Vivo7 software and the distribution of important codes was identified, highlighted and grouped according to major categories and sub-categories developed from the text and a background literature review[1]. Feedback sessions with available participants assisted clarification of whether emerging themes were an accurate reflection of participants' experiences.

Social constructivism, which incorporates a social ecological and holistic approach, was considered during the interpretation and analysis of data [21-23]. The application of social ecological frameworks examines the multiple effects and interrelatedness of several social elements[24] to establish a bigger picture in explaining a phenomenon. This framework explicitly recognises that "the well-being of the individual is predicated on the well-being of the immediate family, which, in turn, is contingent upon community and societal conditions[21,22]. This approach is well suited to Aboriginal health research because it aligns with Indigenous holistic values and considers physical, mental, emotional and spiritual aspects of healing and wellness together for the total well-being of an individual[23].

#### **Discussion**

This paper describes the research approach and methods of a study exploring Aboriginal Australian beliefs and experiences around cancer and cancer services in WA (results are reported elsewhere[25]). The researchers considered and were respectful of key steps of conducting Indigenous research. However, there were limitations, some that could not be overcome. It was not possible, despite the efforts of the researchers, to secure funding beyond one year for the research, which was a major constraint upon providing the optimal means of feedback to

participants and the Aboriginal community; and for research translation. However, to minimise the fact that the project did not get funding for research translation, the findings were presented to Aboriginal community representative forums organised by other organisations and their feedback obtained. Copies of the interviews were sent to some participants and permission was given to other organisations to utilise the study findings in their activities. However, this falls short of the personal feedback to study participants that would be optimal. The long time it takes for data collection, analysis and reporting is another reality for researchers that is not well understood by members of the Aboriginal community.

Funding constrained capacity in other ways; the main interviewer was female whereas ideally an Aboriginal male interviewer may have been important for recruiting male participants and their willingness to talk freely. Many of the ARG members were females, the community-based health workforce are overwhelmingly female, and females are known to attend health services more commonly than males, all of which are likely to have favoured recruitment of more females than males. Another challenge was that the researchers were often dependant on a local person to contact and liaise with the participants on their behalf, which sometimes limited the researchers' choices and opportunities.

The researchers were reliant upon the ARG as a conduit to the Aboriginal community. Coordinating the ARG as a group advisory network proved challenging due to members' individual commitments and work. Aboriginal professionals often have membership on several reference groups for different projects to be managed on top of their core job role, and this can place additional stress and pressure on them. Thus, when group meetings were difficult to convene, members of the group had to be contacted individually which was time consuming and provided input of a different nature to that of a face-to-face meeting.

The Indigenous research paradigm with its need for the research process to be relationship-based, respectful, culturally appropriate and inclusive of Aboriginal people challenged the training and experience in positivist social science of the interviewer. Building the trustworthy relationship with the participants before doing the actual interview created important insights during the research about the life of contemporary Aboriginal people and their concerns.

Presentations of the findings by the researchers needed to be tailored to the audience with the researchers being conscious of balancing their responsibility and obligation to their participants and the wider Aboriginal community with the academic expectations of their disciplines. Where

ever possible, an Aboriginal co-presenter assisted with presentations. There are specific guidelines from journals concerning criteria for authorship and the desire to include Aboriginal authors must be balanced against tokenism. In the current study, authorship issues were given careful consideration and based upon a substantial contribution to the conception, conduct, analysis and writing of the research. One of the authors in this paper is an Aboriginal researcher who was involved with the research and has contributed significantly to publications arising from the study.

Given our commitment to working with the Aboriginal community, it is important to consider how they benefit from this research. Arising out of contacts made during data collection in one regional area, the researchers supported an Indigenous woman to establish an Indigenous Women's Cancer support group[26], and are continuing to work with the group around resourcing and developing a working partnership with mainstream services. There have been opportunities for capacity development of Indigenous people as researchers in the process including them undertaking university postgraduate coursework and research, as co-presenters during presentations in conferences, seminars and lectures and as co-authors on publications arising from this study. Given the dearth of understanding that service providers had of issues relevant to Aboriginal people and cancer, the systematic consideration of the understanding, views and experiences that Aboriginal people have with regard to cancer and that impact upon their access to cancer prevention and treatment services has been important. Information has been disseminated to prompt relevant agencies to improve health and social support in favour of the health and well-being of Aboriginal people. The information and advocacy efforts have influenced policy planners and service providers to acknowledge the need for approaches different to traditional mainstream services. The findings are also informing and assisting the development of appropriate messages with regard to cancer in Aboriginal communities.

Our approach has elements of community-based participatory research which is research conducted as an equal partnership between traditionally trained "experts" and members of a community, and is generally iterative in nature, incorporating research, reflection, and action in a cyclical process[27]. The nature of our research, the research funding constraints, and the many demands upon the small Indigenous population (both community members and health professionals), would create many challenges for truly equitable partnerships. Moreover, community-based participatory research is most likely to be effective in creating change if it arises in the community and has a clear intention to being action-oriented[28].

This seems most likely to be achieved if there is long-term engagement and adequate time and resourcing for each partner, requisites not overcome simply by good intentions.

Western researchers and academics are becoming more appreciative of the need to work with Indigenous researchers as part of decolonising research methodologies and, to incorporate appropriate processes in research with Indigenous people. Some of the key issues of Indigenous research methodology – including the need for being attentive to the culture and traditions of the population they are working with, the necessity to make the process participatory and inclusive of Indigenous communities, the requirement for providing feedback to the community – are equally applicable to other culturally distinct and marginalised communities in the world. However, the profound effect of colonisation on the Australian Indigenous population and its legacy of mistrust and suspicion has a huge impact which needs to be acknowledged and addressed in approaches to Indigenous research. The ongoing challenge is to prioritise responsible conduct of research that ensures a social justice outcome, builds the capacity and develops positive relationships with the researched populations, and creates spaces for Indigenous voices to be heard. This view has also been supported by researchers conducting Indigenous and cross-cultural research in other countries[29].

### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

SS participated in the project's design, carried out the data collection and analysis for this project, prepared the initial draft. DB was involved in writing. PH commented upon drafts of the manuscript. SCT coordinated the whole project, participated in the design and assisted with the conduct of the study and writing. All authors read and approved the final manuscript.

### Appendix

#### Issues explored during interview

##### 1. Journey with the illness

- Experiences with diagnosis, including causes of delayed diagnosis
- Treatment phase
- Coping with cancer
- Recurrence of cancer
- Death and dying

##### 2. On services

- Experiences and issues with the hospitals/health services/cancer services
- Good experience/facilities
- Bad experiences/difficulties/problems with the health system
- How to address the problems they faced in the health services
- What is needed for cancer patients, and Aboriginal cancer patients
- What supports they got and from where
- Any barriers to screening, diagnosis or treatment

##### 3. Perspectives of cancer

- What is cancer
- Causes and aetiology of cancer
- How to get rid of this illness?
- Impact – How it changes someone's life
- Meaning attached to cancer

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**CHAPTER SIX**  
**Findings from the Research**

To Whom It May Concern

I, Dr Lisabeth Finn, was involved in the data analysis phase of the study, **Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia.**

I independently coded some of the transcribed interviews, and then Shaouli and I discussed the similarities and differences and reached into a consensus about the upcoming themes. I actively participated in writing the paper published as:

**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 Serv Res. 2009 Jul 31; 9:132.**

The writing of this paper was led by Shaouli Shahid. I commented upon drafts of this paper and checked the final version of the article.

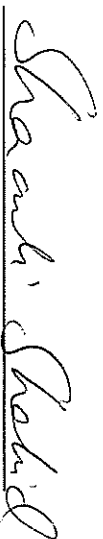
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(Signature of Co-Author)

Dr Lisabeth Finn

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(Signature of Candidate)

Shaouli Shahid



To Whom It May Concern

I, Associate Professor Dawn Bessarab, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia.

I helped Shaouli to interpret part of these findings and commented upon drafts of this paper published as:

**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 Serv Res. 2009 Jul 31;9:132.**

The writing of this paper was led by Shaouli Shahid. I commented upon drafts of this paper and checked the final version of the article.



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Associate Professor Dawn Bessarab



(Signature of Candidate)

Shaouli Shahid

To Whom It May Concern

I, Professor Sandra Thompson, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia since it was started.

I coordinated the whole project, participated in the design and assisted with the conduct of the study. I actively participated in writing the paper published as:

**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 Serv Res. 2009 Jul 31;9:132.**

The writing of this paper was led by Shaouli Shahid. I commented upon drafts of this paper and approved the final version of the article.



(Signature of Co-Author)

Professor Sandra C Thompson



(Signature of Candidate)

Shaouli Shahid

Research article

Open Access

## Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services

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### Abstract

**Background:** Despite a lower overall incidence, Aboriginal Australians experience poorer outcomes from cancer compared with the non-Aboriginal population as manifested by higher mortality and lower 5-year survival rates. Lower participation in screening, later diagnosis of cancer, poor continuity of care, and poorer compliance with treatment are known factors contributing to this poor outcome. Nevertheless, many deficits remain in understanding the underlying reasons, with the recommendation of further exploration of Aboriginal beliefs and perceptions of cancer to help understand their care-seeking behavior. This could assist with planning and delivery of more effective interventions and better services for the Aboriginal population. This research explored Western Australian (WA) Aboriginal peoples' perceptions, beliefs and understanding of cancer.

**Methods:** A total of 37 Aboriginal people from various geographical areas within WA with a direct or indirect experience of cancer were interviewed between March 2006 and September 2007. Interviews were audio-recorded, transcribed verbatim and coded independently by two researchers. NVivo7 software was used to assist data management and analysis. A social constructionist framework provided a theoretical basis for analysis. Interpretation occurred within the research team with member checking and the involvement of an Aboriginal Reference Group assisting with ensuring validity and reliability.

**Results:** Outcomes indicated that misunderstanding, fear of death, fatalism, shame, preference for traditional healing, beliefs such as cancer is contagious and other spiritual issues affected their decisions around accessing services. These findings provide important information for health providers who are involved in cancer-related service delivery.

**Conclusion:** These underlying beliefs must be specifically addressed to develop appropriate educational, screening and treatment approaches including models of care and support that facilitate better engagement of Indigenous people. Models of care and support that are more culturally-friendly, where health professionals take account of both Indigenous and Western beliefs about health and the relationship between these, and which engage and include Indigenous people need to be developed. Cultural security, removing system barriers and technical/scientific excellence are all important to ensure Indigenous people utilise healthcare to realise the benefits of modern cancer treatments.

## Background

A series of reviews recently highlighted differences in the epidemiology and the poorer outcomes of cancer in Indigenous people in Africa, Polynesia and Australia [1-4]. Given the complexity, expense and technology involved in modern cancer treatment, such disparities in cancer outcomes are unsurprising in the developing world. However, in Australia and New Zealand, the differences in cancer survival for Indigenous compared to the non-Indigenous populations warrants further investigation as these countries have well developed health systems offering universal healthcare for their citizens. Aboriginal and Torres Strait Islanders are the original inhabitants of Australia, and often referred to as Indigenous Australians. In this paper, the term Indigenous has been used to refer to first nation or the original inhabitants prior to colonisation in different countries including Australia. However, Aboriginal is the term preferred by vast majority Indigenous people of WA and is used for study participants.

Indigenous Australians have a lower incidence of cancer overall than the non-Indigenous population[3,5] although the epidemiology differs and includes higher rates of cancers with a poor prognosis. The improvement of around 20% in cancer survival in Australia over the last twenty years[6] has not been shared by Indigenous survival figures, with Indigenous Australians 2.5 times more likely to die within five years of cancer diagnosis[7]. The factors underlying these poorer outcomes include health and social disadvantage, health risk behaviours, lower participation in screening programs, later diagnosis of cancer, lower uptake and poorer compliance with treatment and poorer continuity of care[3,8-11]. While the relationship between knowledge, attitudes, beliefs and behaviours is complex, most theories of behaviour acknowledge that beliefs and attitudes have also an important influence upon an individual's decision to access healthcare.

Health, health practices and care-seeking behaviour are culturally bound[12]. Culture is enmeshed in historical, social, economic and political relationships and processes[13] and influences the ways that people understand cancer which, in turn, affects their decision-making around care-seeking and accessing of services [14-18]. Beliefs such as 'talking about something can cause it to happen',[18] screening is unnecessary in the absence of symptoms; relating cancer with black magic; and religious beliefs about destiny have been found to impede early detection and treatment[12,19,20].

The system of health care provision often fails to meet the needs of vulnerable groups. In Australia, Indigenous people are particularly at risk because, on a range of health

and social indicators, they are the most marginalised of any identifiable group. While individual disadvantage is not unique to Indigenous people, it is the coalescence of markers of disadvantage and the resulting health outcomes that make understanding Indigenous beliefs particularly important. Cunningham et al recommended that messages from qualitative studies exploring the views and understanding Indigenous people with cancer must be taken into account[3].

Considerable differences exist in the perception and definition of health, healthy living, wellbeing, illness, and the meaning of disease and death between Indigenous Australians and the dominant Anglo-Australian society [21-23]. Few attempts have been made to systematically explore Indigenous views about cancer[24]. This paper reports the first comprehensive Australian study of Aboriginal beliefs about cancer.

## Methods

### **Ethics approval**

The research adhered to guidelines for ethical conduct of Aboriginal and Torres Strait Islander health research[25], and was approved by the Human Research Ethics Committee (HREC) of Curtin University, the Western Australian Aboriginal Health Information and Ethics Committee, and the ethics committees of the Royal Perth and Sir Charles Gairdner Hospitals. Approval was also obtained from local Aboriginal Health Services. Efforts were made throughout to conduct the study in ways that would build capacity and help equalize power between Aboriginal participants and researchers[26,27]. An Aboriginal Reference Group (ARG) provided input throughout.

### **Data collection**

This was a qualitative study in which the 'meaning of cancer' was explored among Aboriginal people in WA. Participants were Aboriginal males and females who were cancer patients/survivors (n = 14), family members of people with or who had died from cancer (n = 16) and health service providers (n = 7) (Table 1). All spoke English and in-depth interviews between March 2006 and September 2007 explored participants' beliefs and how they felt about and made sense of cancer. A semi-structured interview schedule guided the interviews, with participants encouraged to introduce topics of importance to them. Data collection continued until there was repetition of themes.

### **Data analysis**

The social constructionist framework which emphasizes the complex development and interaction between knowledge, meaning, interpretation and power in the constitution of belief systems[28] assisted understanding

**Table 1: Characteristics of study participants**

Aboriginal Participants (n = 37)	
<b>Area of Residence</b>	
Urban participants	15
Regional participants	22
<b>Category of Respondent</b>	
Patients	14
Family Members	16
Health Service Providers	07
<b>Sex</b>	
Male	8
Female	29
<b>Age (years)</b>	
30-39	5
40-49	19
50-59	9
60+	4

in how the cultural meaning of cancer impacted upon participants' care-seeking behaviour. Social constructionists hold assumptions that individuals develop subjective meanings of their experiences that are guided, to some extent, by their beliefs and understanding which are constructed and negotiated socially and historically[29].

QSR NVivo7 software was used to manage data and support analysis. Thematic analysis of participants' transcribed interviews involved open coding independently by two researchers. Participants' responses were broken down into distinct units of meaning, or codes. Member checking was used to clarify whether emerging themes were an accurate reflection of the participants' experiences. The axial coding stage involved continuous comparisons of codes with one another to discover links between the categories[30], with related categories combined and compared to new data, arranged and rearranged to identify the key themes. To maximize reflexivity and rigour, all stages were discussed within the research team for verification and clarification of emerging themes[31]. Interpretation was assisted by consultation with ARG members and through presentations and feedback at various Aboriginal group meetings.

**Findings**

A range of beliefs were reported, some by most participants while others occurred less commonly. Beliefs foreign to the western scientific paradigm were just as likely to be expressed by urban and educated residents, including those who had worked within mainstream health settings. In reporting, emphasis is given to findings at odds with western medicine or experiences common to many participants.

**Perspectives and understanding of cancer**

*Spirituality and cancer*

Some participants associated cancer with the spiritual world of curses, a form of punishment resulting from some misdeed the person had done in the past. Blaming others or a particular life experience as a cause of sickness is widespread within Aboriginal communities where spirituality exerts a powerful influence upon the notion of wellbeing[32,33]. Such attribution of cancer to spiritual causes can lead to fatalism, acceptance of the disease without question and not seeking help for it – "Aboriginal people have this notion of being sung... it's basically a bad magic put on somebody." As a consequence of such beliefs, people may feel ashamed about their "urong-doing" and hide their symptoms from others, delaying diagnosis or not pursuing treatment [6]. As stated by one family member:

*"...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."*

Relating cancer to spiritual causes is a pre-Enlightenment phenomenon and continues in Indigenous people elsewhere[19,34] and in other cultures[18,35]. It can often work as a coping mechanism to help overcome loss. One participant who had trained as a nurse in telling the story of her daughter's death from cancer talked of her daughter embodying her grandmother's spirit, being sent to explore her grandmother's country and ancestors. The daughter's death was accepted as inevitable, an outcome whispered to her by her mother's spirit long before her daughter's death.

*Fatalism and cancer as a death sentence*

Participants expressed deep fear and fatalistic expectations about cancer: 'cancer equals death'. This belief was considered as a major factor explaining why people ignore early symptoms and do not access treatment even after medical diagnosis.

*"... they are just scared, because at the very end they know they are going to die. As soon as they hear the word cancer they are scared. Cancer is a scary word in the Aboriginal communities."*

Fear of cancer is universal, yet attitudes have changed in most developed countries where messages emphasizing early detection and cure are publicised. Traditional attitudes towards cancer involving hopelessness and death have been replaced by a culture of hope [16], and the belief that cancer is incurable has been largely overcome[36]. However, the pessimistic attitudes towards cancer in this study reinforce similar findings in other Indigenous peoples[19,34,37], with their unfortunate

life-threatening consequences [19]. Participants considered that Indigenous interpretations of cancer as a 'death sentence' reflected the outcomes they have seen.

*"It's sort of like your world crumbles. All we know about cancer is you die from cancer, not so much that cancer can be cured. You always know that as soon as you get cancer you are gone..., you are a goner".*

Few members of their families and communities were seen to survive cancer:

*"I saw my Mum goes through chemo and radiation... I saw my baby brother go through it. I seen my first cousin goes through it, and all my aunties all had cancer, all my mum's sisters. They have all passed away with cancer...."*

Spirituality, fatalism and religion all co-existed. Eight participants said that contracting cancer was beyond the control of an individual, many believing that one was chosen by God to get it.

*"I don't think that it's something you can prevent, it's just people are chosen. ... you can go and have tests every six months, and one day you could just have it and it's been there the whole time..."*

Many cultures hold similar beliefs regarding destiny and God's will[18]. Such fatalistic beliefs are strongly associated with delays accessing pap smears and follow-up of abnormalities[17]. Patients with a fatalistic outlook are less likely to take steps to lower their cancer risk[38], and accept their "imminent demise and refuse potentially life-saving treatment"[16].

Passivity existed alongside fatalism, expressed as belief that nothing could prevent a person from getting cancer: *"When your time's up, your time is up, and you cannot do anything about it"*. One participant emphasized latent internal causes – *'everybody has got cancer cells in their body, but it just takes something to spark it off'*. The participant was not referring to spontaneous cell abnormalities escaping normal immune surveillance[39] but rather elaborated on *"something"* as anything starting from curse, bad spirit, stress and bad luck, very different from the attribution in scientific explanations. Furthermore, such views do not acknowledge health behaviors as known risk factors for cancer[2]. Some participants voiced not wanting to worry about any sickness until they faced it, wanting to continue to live the way they had despite awareness of the associated risks:

*"...you shouldn't stop your life because of all these sicknesses... that's just something that happens, and you deal*

*with it when it comes along... so until then ... just forgetting... laughing..."*.

#### *Unrealistic expectations of treatment*

Contradicting the view 'cancer means death' were comments that Indigenous people accessing cancer treatments often put too much faith in doctors, believing they could fix their health problem. One respondent referred to *"the doctors as gods ...they are the ones that are going to fix it, the miracle-makers"*. This confidence existed without understanding the complexities of cancer staging, co-morbid physical conditions, treatment options and the prognosis of different types of cancer. After finishing treatment, some thought they had been cured, that the cancer had gone and they could get on with their life normally, perhaps not attending for follow-up check-ups. One cancer patient spoke about her mother who believed she was cured by a mastectomy:

*"she keeps saying, 'I have no more cancer... oh they took it all now...' And I keep saying to her, 'Mum, no, it's not true. It's still in your body. Although they took your bubies off, you still got the disease. You got to be careful...."*

Both cancer deaths and recurrences led to disappointment, often considered as an over-reliance or misplaced trust in doctors and western medicine. This could strengthen the distrust Indigenous people commonly feel towards western organisations including doctors and the medical system[40,41]. Personal stories of an individual's disillusionment with the medical system spread in the community, in turn influencing the choices others make around screening, early presentation and treatment for cancer. Distrust and negative experiences in the health system have similarly adversely impacted cancer care-seeking of other minorities[42].

#### *Cancer is contagious*

While not universal, some Aboriginal people believe cancer is contagious. Participants spoke about feeling isolated after diagnosis by the distancing behavior of some friends, family members and others who believed they were at risk of catching the cancer.

*"There was a couple who were really scared of but there was one lady... she actually couldn't sit next to me. She sat across the room from me. She wouldn't talk to me for a long time, because she was scared..."*

Other studies have shown strong links between a person's beliefs about contagiousness, hiding their sickness and avoiding treatment, and feeling stigmatized or fearing being ostracized[19,29]. Although the belief that cancer is contagious is almost non-existent among the general pop-

ulation in WA[36], it can persist among some people from diverse cultural backgrounds[43].

#### *Understanding of cancer*

Fatalistic beliefs and attitudes in the general population have changed as a result of scientific research, dissemination of information and education to help people understand the biological basis of cancer and modern treatment. However, the poorer educational background and socio-economic conditions of many Indigenous Australians have limited their access to information and understanding about disease. A lack of knowledge about types of cancer, symptoms, treatment options and outcomes was apparent, with some respondents having never considered what type of cancer a loved one had. Irrespective of geographic residency, respondents reported not initially recognising the cancer symptoms and delaying getting them checked. One woman had never taken the time to find out about serious illnesses and *"didn't have a clue that it was the start of ...where that brown part puckering up, tightens up."* The idea of self examination, of checking yourself for abnormalities that appeared to be foreign: *"He asked how long I had the lumps (under my arms and neck)...I asked what lumps, I hadn't even felt any lump."*

Attribution of cause for cancer was often unsophisticated:

*"She thought her nose was bleeding because her husband punched her in the nose, and I don't know that she ever understood that it was anything more than that, because that was her experience was, everything was all right until he punched her in the nose and it started bleeding."*

Close family members were often unsure about what was happening to relatives and felt they could have helped more had they been better informed or more knowledgeable. Comments such as *"we didn't know what was happening"* and *"We didn't know that she got cancer until she died"* were common. These comments reflect communication problems for Aboriginal people within health facilities, and ignorance about cancer symptoms such as weight loss, anorexia and bleeding. *"I didn't relate dad's condition to cancer. I found out later when I read up about it ...it was... almost ten years after I lost my dad."*

Working in health services had improved some participants' understanding and knowledge about cancer but they commented on the lack of understanding in the Indigenous community: *"a lot of Indigenous people...I suppose 70 to 80 per cent, wouldn't really know properly."* Another commented:

*"I don't think they understand it. They don't understand about prevention. They don't understand about early detec-*

*tion and screening. Really, I felt that – from working there – some of their experiences or their understanding is so simple, it is very childlike."*

Poor knowledge about cancer warning signs, screening and risk factors among minority populations have been reported elsewhere[17,44,45]. This limited understanding contributes to the many communication gaps between practitioners and patients, increasing patients' frustration with doctors and the medical system.

#### *Perceptions of cancer screening*

Understanding of cancer screening, its purpose and importance was often limited and vague. Ambivalence about participation in screening is unsurprising, particularly if there is a fatalistic view of cancer. As one health worker commented, *"It's a sense that why I am doing a pap smear is to tell them they have got cancer and they are going to die from it..."* Some participants believed that accessing screening would prevent cancers from occurring, with a few viewing screening as an early diagnostic tool. The discomfort and inconvenience of screening, *"fear of knowing"*, *"fear of having their breast squashed"* and the *"shame"* of being touched by another person, were relayed as factors why Aboriginal women do not participate in screening programs. One woman referred to the shame of letting another woman touch her breasts or private parts and concern of being stigmatized as *"lesbian"*. Prohibitions were also in place for men.

*"The prostate thing with the Aboriginal men is... like I say is a 'taboo'... area. They will not go and get a simple test done by the doctor... they feel very funny about it, and so they usually leave it until the last minute, and sometimes that's just too late."*

#### *Urban versus rural/remote differences*

The research explicitly proposed to examine differences in beliefs and understandings of regional compared to urban Aboriginal people who were considered likely to have more acculturation to western understandings. However, the range of views and beliefs did not map readily on the basis of geography or residence. Aboriginal people are mobile and many participants maintain connection with their homeland and culture despite living elsewhere[32,46]. One participant commented about returning to her country:

*"I just feel replenished. My soul is just ... sort of filled up again. I'm home; 'This is where I feel so good.' And it feels good in here. I might not feel healthy. I might have a cold or whatever, but inside I feel ...It just fills me up. It's like a warm bath inside..."*

### Bush medicine and traditional Aboriginal healing practices

Other than a few participants "never brought up that traditional way", use of bush medicines for cancer was widely reported. The Indigenous "holistic view" of life [47,48] in which health is defined as their total wellbeing [49] was frequently iterated: "Healing is not just physical; it's mental, emotional and spiritual as well." For Indigenous people, "a positive outlook and in-look" was considered necessary to be healthy: "If you feel good inside regardless of your health, it will help you in any medical problems". The majority of cancer patients had used bush medicine either sequentially or concurrently[50] with Western medicines.

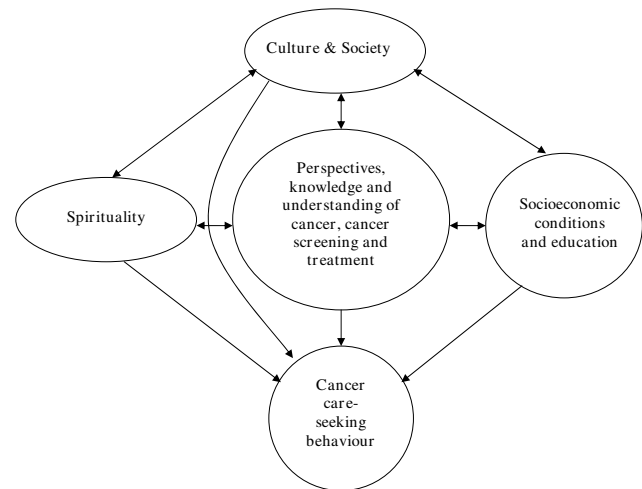
*"There is something in it...that is good for your insides, just as a cleanser. Makes all your body organs healthy and strong, it gets rid of all your internal stress."*

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 palliation, often signifying a re-connection to land, ancestral and spiritual roots that enhanced the person's overall wellbeing.

Use of complementary and alternative medicine is high among cancer patients[51,52]. Certain populations, including Indigenous people worldwide, have their own approaches to healing as part of their culture [50,53]. Western health practitioners need to understand and acknowledge traditional healing and treatment approaches in order to work and communicate effectively with Indigenous patients.

### Discussion

Patients' beliefs influence their care-seeking behaviour for cancer-related services. Considerable literature shows that Indigenous people are often unwilling to use mainstream health services[32], and cancer services are no exception, with lower Indigenous uptake and compliance with cancer treatments. To increase Indigenous people's willingness to accept modern oncology treatments will require a different approach to engaging them in treatment, one which understands and addresses their concerns and provides more psychosocial and holistic care alongside Western medical treatment. Yet to date, understanding Indigenous psycho-social and cultural beliefs and fears about cancer and their impact on care-seeking has been largely neglected despite qualitative methodology being useful for health services research in multicultural settings[54]. The findings from this study align with the social constructionist approach [55], which considers how culture, social life, social interactions and relations shape people's beliefs and understanding about cancer which in turn influences their cancer care-seeking behaviour. This relationship is illustrated in Figure 1.



**Figure 1**  
Meaning-making around cancer and its impact on care-seeking behaviour.

Beliefs, understanding and interpretation stem from shared values, social relations within and between the family and the community, past experiences, cultural identity, and values[56,57]. Like many other cultures[18,58], notions of 'living well', 'sickness' or 'illness' present a complex, dynamic picture in Indigenous populations. Concept of health and wellbeing range from 'absence of symptoms of illness' to a more complex and holistic view of health as the consequence of physical, environmental, mental, and spiritual balance. Lifestyle factors, a person's social relationship with others and harmony with their culture are considered interrelated influences on health[59]. Thus, there is poor compatibility between the underlying principles of the Western reductionist medical system and traditional Indigenous health beliefs[50,59], or even those more recently socially constructed, which shape their care-seeking and willingness to engage with services. Changing community narratives by respecting Aboriginal culture, through education and improving life circumstances and trust of the health system will be important to change the constructs within which cancer beliefs are framed. Health care providers must consider, respect and respond to these needs if they are truly committed to improving Indigenous health outcomes.

The overall pessimistic attitude of Aboriginal people towards cancer as a 'killer' resonates with that of many other cultures [60,61]. Participants' understanding that cancer can often be delayed or overcome with timely Western medical treatment was limited. They had limited access to relevant information, and the shame attributed to cancer and reluctance to talk about it meant stories of



- 
- Recognise cultural diversity and that not everyone has a strong understanding of the biological processes underpinning disease; some cultures have more traditional understandings of causation that are based in tradition and superstition
  - Understand and consider that an Aboriginal patient might have different perspectives towards disease and treatment than a Western-trained doctor, and respect their right to participate in their own care
  - Respect Aboriginal people and culture and show concern for the wellbeing of Aboriginal clients by seeking out and participating in cultural safety training and acting upon it. Encourage other colleagues and service staff to do the same
  - Practice person-centered care. Improve continuity of care and avoid the busyness and business in bed management in ways talk to the patient and close family members to assess their knowledge and understanding about cancer and make comprehensible suggestions
  - Ensure Aboriginal patients' wishes to include their family in discussions are recognised. Address patients and accompanying family members' concerns and misunderstandings with regard to cancer
  - Ensure Aboriginal health staff are included in the treatment team whenever possible. Communicate with the Aboriginal patients in plain language
  - Broach patients' use of alternative and traditional medicine usage and show respect towards patients' use of complementary and alternative medicines
  - Explain to the Aboriginal patients and family members about the possible outcomes and chances from treatment alternatives and help them taking an informed decision
  - Show respect to Aboriginal patients and their family members involving them in decision making regarding treatment initiation and continuation
  - Ensure there are available information materials on cancer which are easy-to-understand, culturally appropriate and available for use with Aboriginal people
- 

**Figure 2**  
**Lessons for health practitioners.**

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survival were not widely disseminated. Appropriately targeted education campaigns, Aboriginal cancer support services and opportunities for Aboriginal survivors of cancer to be advocates in their communities are needed.

Traditional beliefs are not simply displaced by western biomedical understanding, they can co-exist. A study of Indigenous Australian and Papua New Guinean health science students showed that the Indigenous university students conceptualized health and illness in a way which accommodated biomedical science within an integrated scheme of mental, physical and spiritual well-being[59]. Education in western health care did not alter their core philosophy towards life and their spiritual belief system. Therefore, ensuring services are culturally appropriate is important for all Indigenous people, including those with higher levels of education and living in urban areas.

Many Aboriginal people retain a preference for using bush medicine and traditional healing, even for a "western" disease like cancer. The "doctor-dependent, hospital-based, curative western health care model"[58] for treating cancer does not generally recognize, and incorporate traditional systems for healing. However, the combined use of both types of expertise can optimise the response to various health problems, including cancer.

Participants argued for cross-cultural educational initiatives where western cancer support entails an understanding, acknowledgement and acceptance of Aboriginal belief systems and that they are different to western understandings. Aboriginal people also need to understand that western understandings are different. Consideration of cultural differences is essential for health care providers to fully appreciate the impact of this disease on patients' physical and mental well-being. Mutually appreciative understanding of cultural differences is a key to encouraging Indigenous people's willingness to participate in health care to enhance early detection, develop appropriate interventions and ultimately improve cancer outcomes[62].

Paramount to cancer being curable is diagnosis at a stage before spread, when treatments are most effective. The association of cancer with death reflects the tragic reality that Indigenous people are often diagnosed with cancer at an advanced stage, and consequently die within a short period of diagnosis [5,63,64]. Participants commented that some people who develop symptoms consistent with cancer avoid assessment and diagnosis, preferring to hide their symptoms, again a phenomenon not restricted to Aboriginal people[65]. In this way, they avoid confronting their diagnosis and potential mortality for a period of time. This situation needs to be approached through effective education about risks, symptoms and treatments for cancer. In addition, reducing barriers in access, providing more culturally secure health service provision, increasing the visibility of Aboriginal cancer survivorship and focusing attention on the importance of early diagnosis are strategies that can enhance cancer mortality in Indigenous communities.

The study was undertaken only in Western Australia, and it may not reflect the views of Aboriginal people throughout Australia who have different cultural traditions and beliefs. Men were under-represented in our participants which may be due to the primary interviewer being female, the predominance of women among the ARC members and in the community-based health workforce, and the higher utilisation of health services by women compared to men[66,67]. Another limitation was that participants needed to be able to speak English, and this proficiency in English would undoubtedly have some effects on acculturation and exposure to western understandings of health and illness.

**Conclusion**

Beliefs are important but are only one influence on health behaviour. The concept of cultural safety requires a change in emphasis, away from the failings of individual patients (to attend, to comply etc) to critical examination of system factors in health care delivery that may interfere

with an individuals' or a collectivity's willingness to attend a health service or take up treatments that are available. In addition to clinicians needing an understanding of cultural beliefs, a focus on the practice, skills and behaviour of the health system is required so that it appropriately responds to barriers and incorporates "culture" into service delivery[68]. Models of care and support that are more culturally-friendly, where health professionals take account of both Indigenous and Western beliefs about health and the relationship between these, and which engage and include Indigenous people need to be developed[69]. Key lessons for health practitioners are summarised in Figure 2. Only by combining cultural security with technical/scientific excellence and removing system barriers will the potential benefits of modern treatments be realised through increased willingness and ability of Indigenous people to access and participate in healthcare.

### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

SS participated in the project's design, carried out the data collection and analysis for this project, prepared the initial draft. LF was involved in the data analysis phase and writing. DB helped interpret findings, and commented upon drafts of the manuscript. SCT coordinated the whole project, participated in the design and assisted with the conduct of the study and writing. All authors read and approved the final manuscript.

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To Whom It May Concern

I, Dr Lisabeth Finn, was involved in the data analysis phase of the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia.

I participated in writing the paper published as:

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The writing of this paper was led by Shaouli Shahid. I commented upon drafts of this paper and approved the final version of the article.

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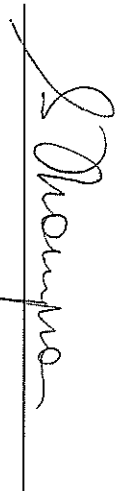
To Whom It May Concern

I, Professor Sandra Thompson, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia since it was started.

I coordinated the whole project, participated in the design and assisted with the conduct of the study. I actively participated in writing the paper published as:

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(Signature of Candidate)

Shaouli Shahid

# Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting

Shaouli Shahid, Lizzie D Finn and Sandra C Thompson

Rates of mortality from cancer are markedly higher for Indigenous compared with non-Indigenous Australians,<sup>1-4</sup> even after adjustment for stage at diagnosis, cancer treatment and comorbidities.<sup>5</sup> Treatment disparity accounts for most of the survival deficit.<sup>6</sup>

Effective doctor–patient communication, particularly crucial in cancer care,<sup>7</sup> positively correlates with the development of a strong therapeutic bond, adherence to therapy, understanding of treatment risks, reduced patient anxiety, patient satisfaction and reduced risk of medical mishaps or malpractice claims.<sup>8-10</sup> Miscommunication can have adverse consequences, including misdiagnosis, procedures being carried out without informed consent, poor adherence to treatment and persistent health-damaging behaviours.<sup>11</sup>

Communication can be adversely affected by people's socioeconomic, historical and cultural backgrounds. Culture is a complex phenomenon encompassing knowledge, folklore, language, rules, rituals, habits, lifestyles, attitudes, beliefs and customs that link and give a common identity to a particular group of people at a specific point in time,<sup>12</sup> and doctor–patient communication can occur in a context where there is interplay between cultures. Concerns about communication between Indigenous patients and health professionals have been previously identified.<sup>13-15</sup> Physicians have been found to deliver less information and less supportive talk to patients of black and Hispanic background and of lower socioeconomic class, and to be less proficient in their clinical performance with such patients.<sup>16</sup> A study with Native Canadians identified history, trust and concept of time as influencing communication between them and physicians,<sup>15</sup> while physicians have documented the significant role of non-verbal communication in interaction with patients of native and First Nations (original inhabitants of Canada and their descendants) ethnicity.<sup>17</sup> If unaccustomed to these non-verbal signals, clinicians could easily misinterpret patient behaviour.

In Australia, few studies have looked at the extent, nature and consequences of (mis)communication between Aboriginal patients and service providers.<sup>11,13</sup> A 2002

## ABSTRACT

**Objective:** To report Aboriginal patients' views about effective communication between Aboriginal people and health service providers in Western Australian hospital settings.

**Design, setting and participants:** Qualitative study involving indepth interviews between 1 March 2006 and 30 September 2007 with 30 Aboriginal people affected by cancer from across WA.

**Main outcome measures:** Aboriginal patients' views about the quality of communication within the hospitals, factors impairing communication and suggestions for improvement.

**Results:** Factors crucial to effective patient–provider communication such as language, shared understanding, knowledge and use of medical terminology require attention. Additionally, communication between Aboriginal people and health care professionals needs to be understood within a broader sociocultural and political context. Fear of the medical system and of being disempowered; mistrust; collective memories of the experience of colonisation and its aftermath; lack of understanding of Aboriginal customs, values, lifestyle and the importance of family and land; and experiences of racism were key issues impairing communication. Health service providers' inability to interpret non-verbal communication and the symbolism of hospital environments also posed problems.

**Conclusion:** Key areas for the attention of health service providers in communicating and caring for Aboriginal people in the hospital setting include culturally sensitive and empathetic personal contact, acknowledgement and respect for Aboriginal family structures, culture and life circumstances, an understanding of the significant role of non-verbal communication, and the importance of history, land and community. Employing more Aboriginal health workers in hospitals, and allowing Aboriginal people to participate at a decision-making level in hospitals is likely to improve Aboriginal people's access to cancer treatment, and would be important symbols of progress in this area.

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study identified sources of miscommunication such as lack of patient control over language, timing, content and circumstances of interactions, differing modes of discourse, dominance of biomedical knowledge, cultural and linguistic distance, and lack of resources including trained interpreters.<sup>13</sup> In this research, we explored Aboriginal people's views and experiences of cancer-related services in WA and their impact on decisions about uptake of cancer treatment.

## METHODS

Our study was approved by four Human Research Ethics Committees. An Aboriginal Reference Group established through invitation was consulted throughout the study period, providing input and feedback from and to Aboriginal stakeholders.

We conducted indepth interviews between 1 March 2006 and 30 September 2007 with urban and regional Aboriginal

adult patients with cancer and family members who had been closely involved in the journey of the Aboriginal person with cancer or who had died from cancer. Purposive recruitment occurred through the networks of the researchers and reference group and through health professionals in primary or tertiary care to ensure inclusion of participants from different regions, sex and cancer types. Limited snowball recruitment (whereby existing participants recruit future participants from among their acquaintances) occurred in rural settings.

All participants spoke English and gave written informed consent. In semi-structured interviews, participants were asked to share the story of their journey with cancer or their journey with a family member with cancer, and to recommend ways of addressing any problems they faced. Difficulties encountered in accessing cancer treatment were explored.

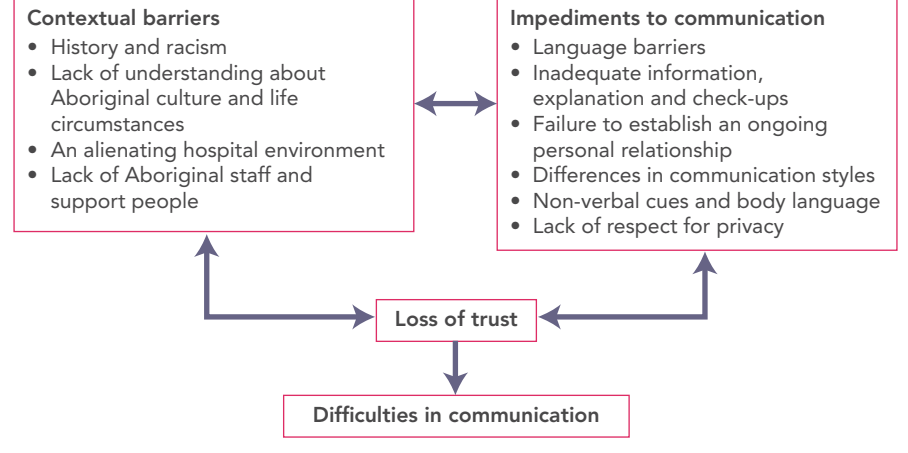




**1 Characteristics of the 30 Aboriginal patients and family members who participated in the study**

Characteristic	Participants
Urban participants	11
Regional participants	19
Patients	14
Family members	16
Male	7
Female	23
Age group (years)	
30–39	4
40–49	18
50–59	5
≥ 60	3

**2 Barriers to effective communication between Aboriginal patients and health service providers in the hospital setting**



In light of Aboriginal Australians’ previous negative experiences with research,<sup>18</sup> relationship building was prioritised and interviews were conducted in a setting of the participants’ choice. On rural visits, a respected appropriate local person nominated by the health service introduced the interviewer, and often remained throughout the interview.

Interviews were audio-recorded, transcribed verbatim and coded independently by two researchers. The interviewer maintained a reflective journal throughout. NVivo 7 (QSR International, Melbourne, Vic) software was used to assist data management and analysis. Participants’ narratives were divided into broad categories to allow identification of key themes. Feedback sessions with available participants clarified whether emerging themes were an accurate reflection of participants’ experiences. A social-ecological and holistic approach was considered for interpreting data.<sup>19,20</sup> Social-ecological epistemology considers the inter-relatedness of several social elements<sup>21</sup> and looks at effects and relationships at multiple levels.<sup>19,22</sup> The holistic approach considers overall wellbeing in terms of physical, mental, emotional and spiritual aspects of healing and wellness.<sup>20</sup>

**RESULTS**

Thirty interviews were conducted with 14 Aboriginal patients with cancer and 16 family members. Demographic characteristics of the 30 interviewees are shown in Box 1.

Thematic analysis identified many concerns relating to hospital treatment. Communication issues with service providers were a salient concern, with subthemes of

contextual barriers, impediments to communication and loss of trust (Box 2). These themes were often coded concurrently, highlighting the connection between them. These results align with the social-ecological model, highlighting the complex interplay between factors at different levels (individual, family, community, societal) and their impact on patient–provider communication. Although many of the issues identified are applicable to non-Aboriginal people when accessing treatment, their severity and impact on Aboriginal people is compounded by an aggregation of factors including their collective historical experience, cultural background and preferences, and poorer socioeconomic circumstances.

**Contextual barriers**

**History and racism**

Racism doesn’t help the process of getting better; it delays it. A lot of our people know. They don’t have to hear it; they can see it in the person’s actions.  
— *Urban female patient*

Underpinning all interactions, including health-related communication, between Aboriginal people and health care providers is a history of ongoing sociocultural and political isolation stemming from colonisation and its continuing, devastating impact on Aboriginal Australians and their culture. Consequently, some Aboriginal people choose not to consider treatment —

Aboriginal women from remote communities make decisions not to come to Perth for treatment because of the way

they are treated here — *Urban female family member*

— or to delay their attendance. Racism and discrimination are frequently experienced by Aboriginal people in contemporary Australia.<sup>23</sup> Participants spoke about disconcerting experiences with doctors’ behaviour and feeling discriminated against (Box 3, A).

Peoples’ views were shaped by both their personal experience and the collective recounted experiences of others.

There were instances when Aboriginal people had to wait on the veranda, sit on the veranda outside the surgery while all the white people were seen to. Aboriginal people would sit there for a whole day and wait... Even if it was freezing cold... — *Urban female family member*

**Lack of understanding about Aboriginal culture and life circumstances**

Participants reported that many providers lacked understanding about Aboriginal culture, and the socioeconomic conditions and life circumstances of Aboriginal families. The importance of extended family and of country was often ignored in the hospital system. Some health professionals were seen as not wanting to deal with attending family members at all. Aboriginal patients’ wishes to be at home for as much time as possible and to die in their country were underappreciated. Doctors had failed to inform some families that a relative had cancer or was gravely ill until days before death. A view reiterated was that terminally ill patients should be informed and offered the opportunity to return home as soon as



### 3 Family members' responses illustrating contextual barriers to effective communication between Aboriginal patients and health service providers in hospitals

#### A. History and racism

"I just couldn't believe that these other doctors' surgeries wouldn't see him! They didn't say why they couldn't see him. Part of it was probably racism... They just didn't want to deal with Aboriginal people." — *Urban male family member*

"... when my sister was having her treatment, we would walk into the chemo unit, being the only three Aboriginal people there, you would have a lot of white people sitting around and they were just staring at you, like, and they don't come and sit next to you." — *Urban female family member*

#### B. Lack of understanding about Aboriginal culture and life circumstances

"... their understanding of Aboriginal culture, Aboriginal history, and just living circumstances is extraordinarily poor among hospital staff." — *Urban female family member*

"... the old lady was in the room and she didn't want to sleep on the bed, she wanted to sleep on the mattress, well, that was a bit hard for the Western world to understand, but that's all they knew is... sleeping on the floor on a mattress." — *Rural female family member*

"In the hospitals... you get where you can only have two people go in. If we were told like only two people... I can understand from the hospital's point of view when they keep the visitors or the communication things to a minimum, but it just sort of causes so many hassles, ... because then the families have to select only a couple of people, and then they have got to tell all of the other fellows... 'No', they can't." — *Urban female family member*

"He wanted to get back to the bush. He had spent all his life in the bush, and that last 7 weeks that we waited down there, he could have got up there". — *Rural female family member*

#### C. An alienating hospital environment and lack of Aboriginal support people

"... they come down and they feel isolated. They are out of their environment, lonely, and never been into a big hospital, so they feel isolated, scared and frightened." — *Urban female patient*

"When my dad was down there it was just like one big grey building. We were just about crying, and so was he. He wanted to get back to the bush." — *Rural female family member*

"I don't think they have got enough Aboriginal people there to work alongside the Aboriginal patients that they have." — *Urban female family member*

"There needs to be some sort of thing in place, there needs to be someone in the medical profession in the different areas that when one of these people are being sent down to Perth they need to be informed. They need to be able to keep in contact with the hospital, with the families, with everybody, even go down with them on the initial visit." — *Rural female family member* ♦

possible (Box 3, B). Furthermore, suggestions by service providers about managing cancer, including taking liquid or "right diet" foods, and refrigeration of medications were sometimes unrealistic, confusing and frustrating.

Putting Aboriginal men and women together, mixing family groups inappropriately, male doctors attending female patients and vice versa, and young(er) providers advising older Aboriginal patients were also culturally inappropriate and problematic (Box 3, B).

#### An alienating hospital environment and lack of Aboriginal support people

Participants viewed the medical system as cold, indifferent, and inflexible. They felt their needs and preferences were not considered important within mainstream service provision (Box 3, C). Many commented on the need for Aboriginal support people to help patients and their families negotiate the hospital system, and to play a significant role in ensuring that patients understood

treatment plans, possible outcomes and responsibilities. Just "having an Aboriginal face around" would help people settle better in the hospitals (Box 3, C).

#### Impediments to communication

##### Language barriers

English is not the language of choice for some Aboriginal people, particularly those from remote communities, yet there are no Aboriginal language interpreter services available in Perth tertiary hospitals. Family or community members may assist, but they may be stressed or lack adequate knowledge to provide informed support for the patient. Some Aboriginal patients lacked any support (Box 4, A).

##### Inadequate information, explanation and check-ups

Some participants had encountered medical staff who failed to explain treatment side effects and the purpose of medications, or who were not forthcoming about the sever-

ity and prognosis of their illness. This angered patients and their families. Physicians' use of jargon and technical terms also caused frustration<sup>24</sup> (Box 4, B), as did perceived avoidance of talking with the patient.

For follow-up appointments, many Aboriginal people had often travelled hundreds of kilometres and waited hours for their check-up, and expected a thorough physical examination. However, some reported having a short 5-minute appointment, with the doctor looking at test results on a computer screen and showing little apparent concern for the patient.

#### Failure to establish an ongoing personal relationship

Staff turnover in hospitals affected continuity of care, impeded development of good doctor-patient relationships and quality of treatment and follow-up services, and disappointed patients. This contributed to patient uncertainty about engagement in treatment and follow-up. Patients felt that the way they were treated during hospital appointments reflected doctors' lack of real care for them (Box 4, C); this is an issue likely to have a particular impact on Aboriginal people because of the importance placed upon relationship within their culture.<sup>25</sup>

#### Different communication styles and non-verbal communication

Participants reported that Aboriginal people are "cluey", "intuitive", "can read minds", and have an ability to pick up whether a provider is genuinely interested in them as soon as they meet. Many physicians were felt to lack compassion or warmth in interpersonal interactions, whereas participants expected them to be "understanding", "compassionate", "concerned" and "empathetic" (Box 4, D). Many Aboriginal people are "reserved" during their visits to doctors, and are reluctant to admit difficulties with understanding (Box 4, D). This reticence could stem from believing that "the doctors know everything", lack of confidence to ask questions, silence as part of their culture or a learned behaviour from previous encounters within mainstream institutions. Such silence could be easily misinterpreted by health care providers.

#### Lack of respect for privacy

Shame and embarrassment about invasion of privacy was another reason why Aboriginal people felt uncomfortable communicating with medical professionals. Ward rounds and teaching sessions with medical students contributed to this discomfort:





#### 4 Interviewees' responses illustrating impediments to communication in hospitals

##### A. Language barriers

"There was another girl directly opposite him in exactly the same condition and she couldn't speak English. So, myself and another person there tried to tell them, 'Get someone down from her community. She needs to be able to communicate. She is in a world on her own. She needs to understand. Talk to her in her own lingo.' She couldn't understand the doctor; she couldn't understand anything. She was full blood. She needed someone from her community there." — *Rural female patient*

##### B. Inadequate information, explanation and check-ups

"... with the remote Aboriginals in the community ... they go home and take this medication and they haven't got a clue what they are taking or what it is for or anything. If you don't understand why you have to do something, sometimes you don't do it." — *Rural female family member*

"If it was explained a little bit more ... not so clinically — and that it's more visual — people can pick up a little bit more, but when it's not and you are just sitting across a table ..." — *Urban female family member*

##### C. Failure to establish an ongoing personal relationship

"You come down here and you don't know the doctors. Each time you come down here it's a different doctor, and that really makes me angry because I have to repeat myself all the time ... If I was to come here and see different doctors each time, they should read my notes before I come in, and not say to me, 'Well, I haven't had time to read your notes. Could you fill me in?' I don't like that at all. It makes me very angry ..." — *Rural female patient*

"They put out so many patients, they see so many patients, it is just like sheep going through the bloody drafting yard or whatever." — *Rural female patient*

##### D. Different communication styles and non-verbal communication

"... as long as they are good and they are friendly, because we are good judges of character. We can tell if someone likes us or is doing something because they just want to do it, or doing it because they care about what they are doing. We can pick that." — *Urban female family member*

"With a lot of Aboriginal people — and I know I have done this myself — if someone is talking to you and explaining to you and they are looking at you and nodding, 'yep, yep', but really it is over your head and you are too ashamed to say, 'No, I don't understand what you are saying', because you don't want to look dumb." — *Urban female family member*

##### E. Lack of respect for privacy

"... just having those 10 people all staring down at you like this, you know, 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." — *Urban female family member*

"A lot of Aboriginal women they don't like anybody touching them ... doctor or anyone. Private parts or whatever; they get embarrassed." — *Rural male patient* ♦

You wake up all you see these doctors there, all these white coats watching over you. I found that a bit embarrassing, and a bit annoying. — *Rural male patient* (Box 4, E).

#### Loss of trust

Issues of apparent medical failure occurred — for example, doctors underestimating symptoms and failing to recommend further diagnostic procedures when indicated by persisting symptoms. The wider failure of the system to deliver good care contributed to mistrust, miscommunication and poorer treatment outcomes.

Conspicuous distrust of hospital services was noticeable. This distrust stemmed from Aboriginal patients' negative encounters and experiences within the health system (Box 5). Trust develops as a result of broad-level

social interaction, and requires reliability of the other within a given context. The absence of manifest respect for the culture of a particular group, together with repeated betrayal of trust, can create further distrust. Once distrust develops, all forms of involvement are undermined. People feel alienated from the system.<sup>26</sup>

#### DISCUSSION

Our study findings indicated that the tools needed to facilitate the entry of Aboriginal people into the medical system and to manage effective treatment are culturally sensitive and empathetic personal contact, acknowledgement and respect for Aboriginal family structures, culture and life circumstances, and the importance of land and community. Although Aboriginal peoples' experiences with cancer are not unique, they

are overlaid by a collective experience of systemic racism within a public health care system.<sup>27</sup> There was considerable commonality in the reports of participants, irrespective of whether they were patients or family members, and despite variation in their demographic backgrounds.

Effective communication between patients and health care providers is essential for quality health care delivery,<sup>16</sup> and is inevitably affected by the culture(s) of those involved.<sup>12</sup> The dissimilarities between Aboriginal beliefs and cultural considerations and the approach of the Western medical system help explain Aboriginal people's underuse of health services.<sup>28,29</sup> Typically, health professionals focus on educating Aboriginal people to increase their biomedical understanding of disease processes. However, if health service providers are to be really effective as "healers", there are strong arguments for their making efforts to understand a patient's culture and social circumstances.

Sensitivity in patient care requires attention to the patient as a person, and this requires focus on patient-provider communication, understanding and relationship. Minorities around the world report less involvement in medical decisions, less partnership, and lower levels of satisfaction with their care providers.<sup>15,16,30</sup>

Limitations of our study include the under-representation of male participants. Possible reasons for this include: the main interviewer being female; women predominating as health care professionals and carers; there being a differential cancer survival according to sex; and higher use of health services by women.<sup>31,32</sup> The larger number of selected quotations from family members suggests that the family members were able to frame the experience of Aboriginal people better, and were more coherent and succinct in reporting.

The higher mortality rate from cancer among Aboriginal Australians reflects the fact that their cancer diagnoses tend to be made later, and their unwillingness to participate in mainstream cancer services. The focus for solving these problems must shift from considering Aboriginal people responsible ("why don't they come") to hospitals and staff accepting a responsibility for ensuring optimal care (including psychosocial care and cultural safety) for Aboriginal patients. The experience reported by Aboriginal participants shows that there is a need for attention at a systems level, and not at the level of the



### 5 Interviewees' responses illustrating loss of trust

"They would have known that, and that is the part that hurts the most, that we could have brought him back up here and looked after him and, yeah, spent that last 7 weeks with him. I feel that we were robbed of that." — *Rural female family member*

"I had three aunties go down there and die. So that sort of got to me, 'You are going down there to die.' They went down there good when you seen them off the plane and the next, what... 3 or 4 weeks after... they died. That's not a good sign for Aboriginal people." — *Rural female patient* ◆

### 6 Suggestions and recommendations based on the study findings

#### At the hospital and system level

- Recruit Aboriginal people onto hospital decision-making committees
- Recruit Aboriginal support people and increase the number of Aboriginal staff in hospitals
- Make the hospital environment more welcoming to Aboriginal people
- Use interpreters or relevant support people to understand patients' concerns and needs
- Improve continuity of care by allowing more time to build rapport, and to know the person
- Provide care and follow-up closer to home where possible
- Increase linkages between the hospital and primary and community-based care
- Make available cultural safety training and encourage all staff, particularly doctors, to attend
- Improve communication skills in oncology staff through training in communication skills and Aboriginal cultural safety
- Rethink how patients are approached for consent around medical and other students

#### For health care professionals

- Mandate participation in cultural safety training so health staff understand and consider Aboriginal cultural needs (behaviours, preferences, importance of family, bond with the land, traditional practice)
- Understand and consider Aboriginal life circumstances such as rural or remote background, food, lifestyle, bond with the land, and the colonial past and its impact, and make realistic suggestions
- Show empathy, kindness and understanding for the person affected by cancer
- Use clear, plain language to communicate with Aboriginal patients and their families
- Explain options clearly and listen to patients' choices
- Make sure that Aboriginal patients and their families have understood what has been prescribed or recommended in regard to cancer treatment, follow-ups and management ◆

individual patient–provider interaction, although the importance of both and the nexus between them is evident. Health care providers who do care have a vital role in creating system reform both inside and outside the hospital, so that the racism, the alienating environment, and the lack of culturally appropriate support, information and understanding reported in this study are addressed. Advocating for more Aboriginal health staff is an important part, and will help overcome current language and communication barriers.

Participants wanted an ongoing, trusting relationship with a provider who genuinely cared about them, but Aboriginal people often felt their wishes were not heeded and that their trust was betrayed. Good care must acknowledge that people care about relational issues such as being treated with dignity and respect and being heard.<sup>33</sup> Trust is crucial for patients in accepting

difficult diagnoses, following complex treatment plans,<sup>34</sup> and for being satisfied with their medical care and having positive clinical outcomes.<sup>35</sup> The system appears to focus too much on clinical competence and too little on other psychosocial characteristics that encourage patient trust — equality, benevolence, integrity, respect, and honesty.<sup>36</sup> If treatment outcomes are to improve, the health system must become responsive to Aboriginal needs and heed their suggestions (Box 6). Participation and representation of Aboriginal people at a decision-making level in hospitals will help ensure these issues are addressed; such inclusion will, in itself, be an important symbol of progress. Increasing Aboriginal health literacy requires access to appropriate information and dedicated employment of Aboriginal staff.<sup>24</sup>

Much of this has been stated many times before, with little action or provision of

resources to match the recommendations and promises. Inevitably, change has opportunity costs, but hospital resources need to be devoted to cultural safety in health care for Aboriginal people. While not challenging the value of randomised controlled trials of oncology treatments, improving (expensive) treatments for some should not be prioritised over the importance of reducing profound health disparities. Change also requires health service staff to undertake greater outreach to Aboriginal communities to build understanding and enhance relationships and support within communities.

Culturally appropriate, integrated and sustainable care for Aboriginal people with cancer requires a coordinated person-centred approach, involving patients, family members, Aboriginal health staff, and clinicians. Relationships developed through such networks are likely to help Aboriginal patients cope with the hospital settings, and ultimately enhance their confidence in communicating with the doctors. Many of the issues raised here are again identified in current national review processes, emphasising that the needs of Aboriginal people are indicative of the need for a broader health care reform process.<sup>37</sup>

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### COMPETING INTERESTS

None identified.

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Artist: Joanne Currie Nalingu (see page 527)



To Whom It May Concern

I, Dr Lisabeth Finn, assisted Shaouli during the data analysis phase of the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia.

I initiated with Shaouli in writing the paper entitled **Shahid S, Finn D, Bessarab D, Thompson SC. "Nowhere to room...nobody told them": Logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment that has been submitted to Australian Health Review.**

I commented and worked upon drafts and approved the final version of the article submitted to the journal.



(Signature of Co-Author)

Dr Lisabeth Finn



(Signature of Candidate)

Shaouli Shahid

To Whom It May Concern

I, Associate Professor Dawn Bessarab, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia.

I commented on drafts of the paper/ publication entitled **Shahid S, Finn D, Bessarab D, Thompson SC. "Nowhere to room...nobody told them": Logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment** that has been submitted to Australian Health Review.

I also checked the final version of the article submitted to the journal.



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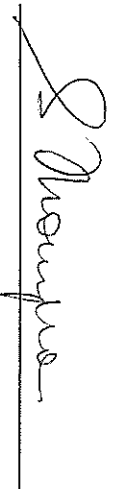
Shaouli Shahid

To Whom It May Concern

I, Professor Sandra Thompson, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia since it was started.

I coordinated the whole project, participated in the design and assisted with the conduct of the study. I actively participated in writing the paper entitled **Shahid S, Finn D, Bessarab D, Thompson SC. "Nowhere to room...nobody told them": Logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment** that has been submitted to Australian Health Review.

The writing of this paper was led by Shaouli Shahid in conjunction with Dr Lisabeth Finn. I commented and worked upon drafts and approved the final version of the article submitted to the journal.



(Signature of Co-Author)

Professor Sandra C Thompson



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Shaouli Shahid



**“Nowhere to room...nobody told them”: Logistical and cultural impediments to Aboriginal peoples’ participation in cancer treatment**

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## **ABSTRACT**

**Background:** Cancer mortality among Indigenous Australians is higher compared to the non-Indigenous population and attributed to poor access to cancer detection, screening, treatment and support services. A large proportion of Indigenous Australians live in rural and remote areas which makes access to cancer treatment services more challenging. Factors, such as transport, accommodation, poor socio-economic status and cultural appropriateness of services also impact negatively on health service access and, in turn, lead to poor cancer outcomes.

**Design, setting and participants:** Qualitative research with 30 in-depth interviews conducted with Aboriginal people affected by cancer from across WA, using a variety of recruitment approaches.

**Results:** The infrastructure around the whole-of-treatment experience affected the decision-making and experiences of Aboriginal patients, particularly impacting on rural residents. Issues raised included transport and accommodation problems, travel and service expenses, displacement from family, concerns about the hospital environment and lack of appropriate support persons. These factors are compounded by a range of disadvantages already experienced by Aboriginal Australians and are vital factors impacting on treatment decision-making and access.

**Conclusion:** To improve cancer outcomes for Aboriginal people, logistical, infrastructure and cultural safety issues must be addressed. One way of ensuring this could be by dedicated support to better coordinate cancer diagnostic and treatment services with primary health care services.



## INTRODUCTION

Death rates for Indigenous<sup>a</sup> Australians are three times higher than for non-Indigenous Australians<sup>1, 2</sup>, with markedly higher cancer mortality rates<sup>3-6</sup>. Poorer Indigenous cancer outcomes are occurring despite advances in detection and treatment techniques and overall improvements in cancer outcomes in Australia<sup>7</sup>. Indigenous Australians are less likely to access cancer screening; diagnosed at a more advanced stage of cancer; have poor continuity of care; lower compliance with treatment; and lower five-year survival rates<sup>4, 8, 9</sup>. This situation clearly warrants consideration and appropriate action by both primary health care services and cancer treatment services.

Health service access is an important determinant of health outcomes for both preventive care and treatment<sup>10, 11</sup>. Access to health care is particularly difficult in geographically extensive territories like Australia<sup>1</sup> where many people need to travel large distances to health centers and services<sup>12, 13</sup>. Extremely heterogeneous geography of Western Australia (WA), in particular, comprises vast regions of sparsely populated and mostly uninhabitable areas and small isolated rural towns and larger regional centers. Vast distances separate many of these localities, often in combination with very small population base<sup>14</sup>. Poorer access to cancer detection, screening, treatment and support services for rural and remote people as compared to urban dwellers, is a primary reason for a reduced likelihood of cancer survival<sup>2, 15</sup>. Health care in rural and remote WA is mostly delivered by government salaried General Practitioners (GPs) or District Medical Officers (DMOs) from the regional hospitals. They travel to remote communities. Occasionally salaried GPs work in those areas. Specialist treatment usually involves transport of patients to larger centers (usually Perth or Darwin). Transport of patients to central areas, and of health workers to remote areas, is often delivered by the Royal Flying Doctor Service<sup>16</sup>. Thus, poorer cancer outcomes for Indigenous Australians are compounded by the rural and remote residency of over half of Australia's Indigenous people.<sup>2, 17</sup>

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<sup>a</sup> In this paper, the term Aboriginal has been used to refer to the Indigenous people of WA. We have used Indigenous when we are referring to features that are identified across different Indigenous peoples

This paper utilises information from research undertaken to investigate the experiences and barriers of Aboriginal people in accessing cancer services and treatment in WA. An explicit aim of the research was to explore differences in experiences for Aboriginal people based upon their residence in urban, rural or remote settings. Basic infrastructure and logistical problems in accessing hospital-based treatment along with communication issues<sup>18</sup> and lack of culturally appropriate service delivery mechanisms were frequently mentioned by the participants. Inevitably, additional problems were reported by those who travelled from rural areas to receive cancer assessment and treatment. This paper focuses on what could be considered as infrastructure necessities for Aboriginal patients on their cancer journey including transport, accommodation, preparation for hospital-based cancer treatment, service affordability and support services. The study outcomes indicated that reconfiguration of cancer care, with a greater emphasis on support in local communities and better coordination with primary health care services is necessary to improve Aboriginal patient outcomes.

## **METHODS**

### **Ethics Approval**

Ethics approval was obtained from the Human Research Ethics Committee of four organisations including the Western Australian Aboriginal Health Information and Ethics Committee. An Aboriginal Reference Group (ARG) consisting of Aboriginal health professionals was established, involved and consulted throughout the study period.

### **Data Collection and Analysis**

The research design ensured a culturally sensitive research approach by involving and supporting Indigenous people<sup>19</sup>. Descriptive qualitative research methods were utilised. Prior to commencement of the interview, steps were taken to ensure an introduction from someone trusted and known by the participant, build rapport and develop a relationship. Participants were encouraged to tell their story in describing their cancer journey. This mode of data gathering known as „yarning’ is an acceptable means of gathering data, aligning with Indigenous cultural oral traditions

offering Indigenous people a voice by applying a non-threatening research paradigm<sup>20</sup>.

Thirty in-depth interviews were conducted between March 2006 and September 2007 in Perth (urban) (n=11) and in one rural (9) and two remote areas (7) of WA. Several patients from other areas of WA who came to Perth for treatment around this time were also interviewed (n=3). Aboriginal interviewees were adult cancer patients, survivors (14) and family members (16) of people with cancer or people who had died from cancer. A detailed description of the recruitment strategy and data collection processes are described elsewhere<sup>19</sup>.

All participants could speak English and gave written informed consent. Participants were asked to share the story of their journey with cancer (either personal journey with cancer or journey with a family member who had cancer), including their experience with diagnosis and treatment, and to suggest strategies to better manage the problems they faced. The semi-structured interview guide explored difficulties in accessing treatment.

Interviews were audio-recorded, transcribed verbatim and coded independently by two researchers before members of the team conferred. The interviewer maintained a reflective journal throughout. Thematic analysis was chosen to analyze the data in that it allows a rich overall thematic description which is useful when an under-researched area is being investigated<sup>21</sup>. NVivo7 software was used to assist data management and analysis. Participants' narratives were divided into broad categories to allow identification of key themes and discussed by the research team. Feedback sessions with available participants assisted clarification of whether emerging themes were an accurate reflection of participants' experiences.

## **RESULTS**

A key theme identified in the analysis was the need for instrumental and emotional support in all aspects of the cancer journey. This was particularly the case in relation to the whole-of-treatment infrastructure and to practical logistical issues relating to all aspects of treatment. Difficulties encountered in these areas determined the

experience of treatment - particularly for rural/remote Aboriginal patients. Issues included problems with transport and accommodation arrangements, particularly the hospital environment and Aboriginal support/liaison. The expense of treatment and medication costs was also raised. Not all experiences were negative with some positive experiences described when individual needs were met. Some participants recommended strategies towards better meeting Aboriginal needs.

## **Transport**

*“They don’t know which end of Perth [city] is left, right or centre...like when people come to Perth they say „Just go to the hospital. How do people know where the hospital is... especially some people who have never left their home town.”* (Remote, Male patient)

Many interviewees spoke about rural and remote Aboriginal people who travelled to an urban centre for cancer treatment; people often arrived feeling disoriented and scared with many having travelled hundreds of kilometres over several days involving numerous changes of transport. These long journeys were viewed as deterring Aboriginal cancer patients, particularly older and more traditional people, from leaving their community to access the treatment they needed: *“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.”* (Urban, Female family member)

Rural and remote Aboriginal cancer patients, some of whom had never left their home community, saw the journey and stay in an urban centre as akin to landing on the moon. Some participants reported that patients were sometimes just handed an air ticket and a taxi fare and told to head for the hospital. *“They just say „get to the airport and when you get to the airport [on arrival] you get a taxi and it will take you to where you are going to stay....”* (Remote, Male patient) One participant observed that some Aboriginal people were unfamiliar with different aspects of travel, such as using toilets on planes or pay telephones along the way. Some were terrified by speeding along a city freeway in a bus or a taxi. Remote residents often had no idea of the distance, costs of taxis and other expenditure in an urban area. These additional expenses rapidly diminished money which was needed for food or accommodation.

Even patients who lived in Perth had problems accessing cancer treatment services. There were problems with the cost of transport and parking, the time required to travel from outer metropolitan areas and availability of public transport.

### **Accommodation**

*“We get down there and we have got nowhere to stay. My niece, she lives in Perth, and she is an hour away from Charlies, so we don’t even bother going there...too far”* (Rural, Female family member).

Accommodation while participating in cancer treatment is important. Schedules for chemo- and radiotherapy vary but appointments can spread over months and occur sequentially. Rural participants reported difficulty finding accommodation on arriving in a city. The picture emerged of a system where sometimes referral arrangements were poor, with the hospital unaware they were coming and accommodation bookings not made. Aboriginal patients sometimes got lost in the system, both for their initial and follow-up treatments. In a city that was strange and alien, many non-urban Aboriginal patients were expected to buy food and cook for themselves while staying in hostel accommodation. Grocery shops were not close to some of the accommodation, and at a time when they were not well, patients might need to catch a bus or to walk some distance to buy food.

One participant reported she had refused to stay in an Aboriginal hostel as she didn’t know the hostel residents; they were strangers. Reports indicated that when accommodation failed, Aboriginal patients often aborted their treatment. They did not access available 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”* (Remote, Male patient).

Relocating for treatment could be particularly difficult for women with children. For example one woman whose child had to attend hospital in Perth for cancer treatment had four other children who had to accompany 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. She had to withdraw her children from school and

because she couldn't drive, trips to the hospital to visit her child were not easy. There are no childcare facilities associated with the adult teaching hospitals in Perth.

## 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”* (Rural, Female family member).

Many participants described the hospital environment as alienating. When Aboriginal patients arrived for their treatment, some participants reported they were just given a map of a big hospital which for them was akin to being in a strange city. It was difficult for them to navigate their way around and even more difficult if they were unable to 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. Hospital food was also an issue raised by a number of participants: *“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, „k kangaroo going to be served?”* (Urban, Female family member).

Older Aboriginal men seemed to find the hospital regime and dependency particularly disempowering. One participant said her 84-year old grandfather *“hated being heavily dependent on strangers”* in hospital as 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.

Perhaps one of the greatest difficulties experienced was the lack of hospital flexibility for extended family who wanted to give ongoing support to a patient. Hospital staff restricted the number of people allowed in a ward room. This was particularly difficult 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...”* (Urban, Female family member).

Embarrassment about invasion of privacy in hospital caused shame and discomfort for Aboriginal patients. Teaching sessions with medical students and ward rounds contributed to this discomfort “...*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*” (Urban, Female family member).

### **Expense of medication and treatment**

*“In the real world we can't order MRIs and things like that, and most of these things do attract an excess. A CT scan and most X-ray people, there is quite an extra amount of money you have to pay which our patients can't afford.”* (Urban, Female family member)

Indigenous patients have much lower rates of private health insurance, with the 2001 National Health Survey showing that 17% of Indigenous Australians in non-remote areas had private health insurance compared with 51% of other Australians<sup>22</sup>. This reduces the access of Indigenous Australians to specialist care, private hospitals and the services available to private patients. Yet many cancer treatments are expensive and either unavailable or have long waiting lists in the public system. 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 subsidized medication, but even then it was very expensive. Ultimately, the participant started paying for her sister's medication on a credit card because she could not afford to get it any other way.

### **Aboriginal support and liaison**

*“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.”* (Remote, Male patient)

The need in the mainstream hospital system for patients and families to get direct practical and emotional support from an Aboriginal person was emphasized. There was a lack of Aboriginal interpreters or Aboriginal Liaison Officers (ALO) to accompany Aboriginal patients, provide information and make them feel more

comfortable about the whole process of cancer treatment. 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 a place where they knew no-one. The need for emotional and psychological support at this time was a consistent theme. However, health service rules, costs and family responsibilities often precluded a family member being able to accompany them. One participant referred to the need for regional ALOs to explain the treatment program and what it entailed to Aboriginal people before they travelled. 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*” (Remote, Male patient).

For rural cancer patients returning to their communities after cancer treatment, respondents reported that follow-up supports such as physiotherapy, practical information on post cancer treatment and counseling were lacking. There were often communication breakdowns between the primary care service and the tertiary hospital with appointments made by the tertiary hospital for treatment and follow-up with little understanding of where the person lived, and the time and expense of travel. Appointments were arranged without involving the primary care service which, in many cases, could have helped to organise logistical support for the patient to attend follow-up appointments.

### **Positive support experiences**

Some participants reported positive experiences regarding support for issues of transport and care. This included payment by the Patient Assisted Travel Scheme (PATs) for an airfare or fuel costs and contribution towards accommodation costs. Other participants, especially those from rural and remote areas, praised palliative care and home-nursing services. Participants appreciated this support because of 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” (Urban, Female family member)*

Other supports included that provided by local Aboriginal Medical Services, access to wigs from the Cancer Council and installation of amenities by Disability Services to assist patients affected by treatment or illness. A few participants talked about the extensive support they received from the Social Work department within the hospitals: arranging accommodation, maintaining links with family during treatment, access to discounted food supplies and assistance with returning home. However, it became evident that families who had connections with the health system due to their work and had sufficient familiarity with health and related support services to be able to negotiate the system were most likely to benefit from such services. This reflected that many Aboriginal participants did not ask for support services because they did not know about them, or because they were intimidated or overwhelmed. Unfortunately this often meant they did not receive them, suggesting there were inadequate proactive mechanisms around access to support services.

## **DISCUSSION AND RECOMMENDATIONS**

Many Indigenous people are reluctant to seek medical attention until their condition is serious<sup>23</sup>, and this is true for a life-threatening disease like cancer. Modern cancer treatments utilise high technology medicine for diagnosis and treatment and are carried out in tertiary hospitals which in WA are all based in Perth. While logistical issues are inevitable for all Australians who need to travel long distances to access health services, the difficulties encountered by participants in this study were compounded by the profound disadvantages experienced by Indigenous people across a broad range of indicators. Both financial disadvantage and socio-cultural barriers contribute to making the journeys of Indigenous Australians particularly difficult<sup>3, 11, 24, 25</sup>. The literature recognizes logistical, practical and economic difficulties impacting negatively on Indigenous Australian access to cancer treatment services<sup>24-26</sup>.

Our study found that Aboriginal patients from rural locations who travel for cancer treatment can feel distressed and demoralized. Service affordability including medication, care costs and dislocation from family compound the problem. While the

PATS offers some financial assistance for rural and remote travel there are still many Aboriginal people who slip through the gap. Many participants found the PATS system complicated and were unclear and unsure about what was covered by PATS and what was not; some reported experiencing difficulties when dealing with the supported travel system. These findings concur with the conclusions of a review conducted by WA Country Health Service in 2006<sup>25</sup>. However, it is worthy of note that the majority of the Aboriginal population in Perth who live predominantly in outer urban areas also need to travel for treatment; they do not receive any reimbursement for their travel costs. It is highly likely that if people think they can't 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.

Compared to non-Indigenous remote dwellers, remote-dwelling Indigenous patients have significantly higher rates of cancellation and non-attendance at hospital appointments and frequent premature hospital discharge against medical advice<sup>24, 25</sup>. These attendance disparities indicate that it is not distance *per se* that impedes access to care, but the lack of mainstream treatment infrastructure to fulfill the specific needs of Indigenous Australian patients.<sup>13</sup> Issues of communication, trust and the cultural safety of mainstream health services have been discussed elsewhere<sup>18</sup> and require urgent expeditious consideration if Indigenous cancer outcomes are to be improved.

Many of the issues raised by participants related to these infrastructure issues and the quality of care in the hospital setting. There have been calls for the current structural and financial arrangements that operate for cancer care provision to be reformed<sup>27, 28</sup>. This would include making primary care providers the coordinators of care within a multidisciplinary team environment. In this role they would be more able to service the holistic needs of patients, an arrangement which is particularly important for those who are most vulnerable. It also needs to be recognised that properly resourced, well managed Aboriginal Health Services would be ideally placed to provide the sort of support our patients need, and many no doubt already do. Aboriginal Community Controlled Health Services (ACCHSs), known as Aboriginal Health Council of WA (AHCWA) in WA, was established to improve access to health services for the local Aboriginal community by creating a culturally

appropriate environment<sup>29</sup>. Case conferencing (either by video or telephone) between cancer specialist and 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. Case conferencing has been proved as an excellent tool for immediate problem solving, and for improving immediate care of a patient with a chronic and complex condition. Case Conferences have the same eligibility criteria as for care plans, and are comprised usually of a medical practitioner and at least two other health and/or community providers, each of whom provides a different kind of care<sup>30</sup>.

There are other ways that primary care providers can assist Aboriginal cancer patients and their families. It was evident in this study that patients often arrived at the hospital door, completely unprepared for the experience. Yet being aware in advance of what will happen and likely lengths of stay in hospital could help Aboriginal patients to be both physically and psychologically prepared for their stay. 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 with understanding and adjustment. This has been clearly mentioned by Lawrence and colleagues who have demonstrated the importance of the principles of patient-centred care, cultural respect and systemic continuous quality improvement. They have emphasized the need to recognise that different patients have different needs and to make respectful systemic adaptations in order for best outcomes to be achieved for Aboriginal people with heart disease<sup>31</sup>. Similarly, there is evidence that efforts in improving discharge planning are effective and improve the interface between hospital and community care<sup>32</sup>.

Indigenous people suffer higher morbidity from chronic diseases that could have been prevented had they grown up in an environment unmarred by socio-economic disadvantage and exclusion and where diseases were identified earlier and managed better. Poorer access by Aboriginal patients to health services compounds this problem. This challenge needs to be addressed by improving access to comprehensive primary health care which can provide a culturally secure service. Development and access to effective and culturally appropriate primary care, which understands and can provide appropriate support, is an important prerequisite for

intervention and medical care at an earlier stage of disease. It is also essential for follow-up care after assessment and/or treatment in a specialist cancer centre.

The barriers faced by many Indigenous people in accessing specialist and hospital care are substantial. A cancer diagnosis is distressing enough, yet many Indigenous people will face extra stress before and during treatment. The psychological and physical health impacts of an inadequate and inappropriate structure of care are profound. Enough is known about the needs of Aboriginal people to require that oncology service providers broaden their focus beyond biomedical care to ensuring that the psychosocial and practical needs of Aboriginal patients are adequately met. The infrastructure needs described in this paper will be addressed if care is truly patient-centered and respectful of an individual's culture and circumstances. These reforms are more likely to be expedited by an overall system reform which would take steps, firstly to include Aboriginal workers as part of the care team, proactively considering a patient's need for social and welfare support; and secondly, to increase awareness and understanding by health care providers about the historical and contemporary challenges facing Aboriginal people in accessing culturally-safe care.

## **Box 1: Suggestions and Recommendations**

### **Transport**

- Increase awareness of health service providers about the impact that distance and travel is likely to have on clients
- PATS program to be better promoted and entitlements made clearer to users
- The process of claiming PATS should be simplified and 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 means 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
- Provide a welcome to country from a Noongar Aboriginal elder as part of arrival in the metropolitan area

### **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 are proactive 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.

### **Hospital Environment**

- Improve the hospital environment and make it welcoming for Aboriginal people by providing a culturally sensitive environment (through 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

**Aboriginal Support and Liaison**

- Consider patient advocates or navigators to provide support and assistance to the patient and their family by negotiating system barriers
- Provide information and help in with accessing relevant support agencies

**Transfer of Care**

- 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

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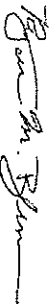
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To Whom It May Concern

I, Ryan Bleam, was involved in the preparation of the initial draft of the paper/ publication entitled **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** that has been submitted to Journal of Ethnobiology and Ethnomedicine.

I also checked the final version of the article submitted to the journal.



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To Whom It May Concern

I, Associate Professor Dawn Bessarab, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia.

I commented on drafts of the paper/ publication entitled **Shahid S, Blearn 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** that has been submitted to Journal of Ethnobiology and Ethnomedicine.

I also checked the final version of the article submitted to the journal.



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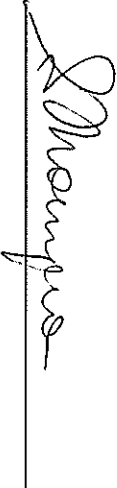
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To Whom It May Concern

I, Professor Sandra C. Thompson, was involved with the project, Towards Understanding Disparities in Cancer Outcomes for Aboriginal Australians: Exploring Aboriginal Perceptions and Experiences of Cancer in Western Australia since it was started.

I coordinated the whole project, participated in the design and assisted with the conduct of the study. I actively participated in writing the paper entitled **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** that has been submitted to Journal of Ethnobiology and Ethnomedicine.

I also checked the final version of the article submitted to the journal.



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RESEARCH

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# "If you don't believe it, it won't help you": use of bush medicine in treating cancer among Aboriginal people in Western Australia

Shaouli Shahid\*<sup>1,2</sup>, Ryan Blears<sup>1</sup>, Dawn Bessarab<sup>1,2</sup> and Sandra C Thompson<sup>1,2,3</sup>

## Abstract

**Background:** Little is known about the use of bush medicine and traditional healing among Aboriginal Australians for their treatment of cancer and the meanings attached to it. A qualitative study that explored Aboriginal Australians' perspectives and experiences of cancer and cancer services in Western Australia provided an opportunity to analyse the contemporary meanings attached and use of bush medicine by Aboriginal people with cancer in Western Australia

**Methods:** Data collection occurred in Perth, both rural and remote areas and included individual in-depth interviews, observations and field notes. Of the thirty-seven interviews with Aboriginal cancer patients, family members of people who died from cancer and some Aboriginal health care providers, 11 participants whose responses included substantial mention on the issue of bush medicine and traditional healing were selected for the analysis for this paper.

**Results:** The study findings have shown that as part of their healing some Aboriginal Australians use traditional medicine for treating their cancer. Such healing processes and medicines were preferred by some because it helped reconnect them with their heritage, land, culture and the spirits of their ancestors, bringing peace of mind during their illness. Spiritual beliefs and holistic health approaches and practices play an important role in the treatment choices for some patients.

**Conclusions:** Service providers need to acknowledge and understand the existence of Aboriginal knowledge (epistemology) and accept that traditional healing can be an important addition to an Aboriginal person's healing complementing Western medical treatment regimes. Allowing and supporting traditional approaches to treatment reflects a commitment by modern medical services to adopting an Aboriginal-friendly approach that is not only culturally appropriate but assists with the cultural security of the service.

## Introduction

*Indigenous Peoples' concept of health and survival is both the collective and individual inter-generational continuum encompassing a holistic perspective incorporating four distinct shared dimensions of life, which are the spiritual, intellectual, physical, and emotional. Linking these four fundamental dimensions, health and survival manifests itself on multiple levels where the past, present and future co-exist simultaneously*[1]

The holistic health care system has been practiced by people from different ethnic and cultural background

worldwide[2]. While these health systems in various parts of the world share certain characteristics that distinguish them from biomedicine, approaches to health and healing are diverse and changing over time. Nevertheless, some commonalities can be distinguished [3]. In Australia (as elsewhere), Aboriginal people have relied on plants for many of their needs, including as a medicine in treating their ailments[4]. Aboriginal and Torres Strait Islander people are the Indigenous people and original inhabitants of Australia. In this paper, 'Aboriginal' has been used to refer to the Aboriginal and Torres Strait Islander people who are traditional inhabitants and Indigenous people of Australia. 'Indigenous' has been used when we refer to descendants of the native or first nation inhabitants of other countries prior to European

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colonisation. Since colonisation, the lifestyles of Aboriginal Australians have endured significant change through dispossession of land, social disruption, racism, cultural suppression and discriminatory government policies[5]. Consequently, people's usage of plants and maintenance of traditional cultural beliefs and practices, including traditional medicine and healing practices[6] have varied according to the impact of colonisation on their connection to country and culture. Previous research confirming the use of traditional medicines[6,7] by Indigenous people have recognized that failure to understand and communicate about such usage may result in patients' dissatisfaction and non-compliance with existing biomedical treatment services[8,9]. This however, has not translated to mainstream health service providers who appear to have little recognition and acknowledgement of the belief in and use of traditional healing practices and medicines by Indigenous patients[10,11].

This analysis arose in the context of a research project that aimed to explore the beliefs, understanding and meaning of cancer to Aboriginal people in Western Australia (WA) and their experiences with cancer services. Although the use of bush medicine was not a particular focus of the study a number of participants raised the issue of using traditional healers and bush medicine for cancer during their interviews.

This paper provides an overview of the use of bush medicine and traditional healing amongst Aboriginal Australians for their treatment of cancer and the meaning attached to it and argues for health service providers to recognize its importance in the life of Aboriginal people, especially during consultation. Effective and culturally sensitive health care provision for Indigenous communities requires respect for patients' beliefs and practices of healing. Healing is 'a process that brings parts of one's self (physical, emotional, mental and spiritual) together' which 'can result in an integrated and balanced whole self'[12]. Thus, it includes ceremonies, traditions, values and ideas related to Indigenous culture[12]. There exists limited written information on such healing traditions in Aboriginal Australian communities as secrecy and mysticism are attached to the use and origin of such practices and medicines.

### **Aboriginal Australians and Cancer**

In recent years there has been an increased priority given to Aboriginal cancer in mainstream health[13]. When compared to the difference in life expectancy between Aboriginal and non-Aboriginal Australians[5], cancer is now one of the leading causes of death amongst the Aboriginal population[14,15]. For many years cancer was not prioritized as a health issue, primarily because of the low life-expectancy of Aboriginal Australians and more immediate and obvious health problems. Overall, the lit-

erature suggests that the incidence of various cancers is lower in surveillance research data[16,17] in part due to the misclassification of Aboriginal status in cancer registries[18]. Additionally, as a small minority of the total Australian population[16], it is difficult to provide statistically significant figures for Aboriginal Australians. Selected data are available for some cancers, including a five times higher mortality rate for women's cervical cancer[16], and almost two times higher incidence rate of liver cancer than that of non-Aboriginal Australians. The limited available data highlights a need for more attention to be given to Aboriginal cancer.

Aboriginal Australians with cancer are twice as likely to die from the disease than non-Aboriginal Australians[19]. This could be due to the fact that Aboriginal people are diagnosed later than their non-Aboriginal counterparts; have poorer continuity of care and a lower compliance with treatment[15,20]. They also suffer from cancers which generally have a poor prognosis but are largely preventable[15]. The late diagnosis has been attributed to a general fear of check-ups and screenings[21,22]. Some of the traditional beliefs surrounding sources of illness attribute the cause of disease to acts of spiritual punishment, sorcery, payback, taking something from country or trespassing on a significant site[23,24]. Payback and sorcery may be bestowed upon those who do not fulfil social obligations or break a moral taboo[25]. These forms of cultural punishments could explain the reluctance of some Aboriginal people to seek early intervention for their illness due to a fear of community shame. Although such beliefs are primarily held in remote and traditional areas, these views are also held by urban and metropolitan Aboriginal populations[25,26].

Late diagnosis and discontinuity of treatment can also occur due to the fact that the hospital setting is a source of social unease for Aboriginal patients[25,27]. The practitioner's waiting room can present as a foreign environment where Aboriginal patients may experience themselves as outsiders in a sterilized, Western clinical setting. Additionally the thought of a 'private consultation' singles out the patient and creates further discomfort and shame. As many studies [6,25,27,28] have pointed out, shame (a violation of cultural or social values so it is possible to feel ashamed of thought or behavior that no one knows about) is a unique and powerful emotion to Aboriginal Australians. Another form of shame can come from gender-specific issues and the resistance to being examined or having to talk about symptoms with someone of the opposite sex[25,27]. Shame is also associated with cancer because many Indigenous people feel it is a 'white man's disease' [23,28-30]. This sentiment may discourage Indigenous people from believing they are at-risk of cancers[23] or may prevent them disclosing their illness to others[24,28].

**Table 1: Characteristics of Study Participants**

Aboriginal Participants (n = 37)		Aboriginal participants who made mention about bush medicine (n = 11)	
<b>Area of Residence</b>		<b>Area of Residence</b>	
Urban participants	15	Urban	6
Rural participants	9	Rural	3
Remote participants	8	Remote	2
<b>Category of Respondent</b>		<b>Category of Participants</b>	
Patients	14	Patients	4
Family Members	16	Family Members	4
Health Service Providers	07	Health Service Providers	3
<b>Sex</b>		<b>Sex</b>	
Male	8	Male	2
Female	29	Female	9
<b>Age (years)</b>		<b>Types of cancer treated</b>	
30-39	5	Breast	3
40-49	19	Cervical	2
50-59	9	Head and Neck	1
60+	4	Lung	2
		Unknown	1
		<b>General mention about bush medicine</b>	2

In Indigenous belief systems, health is closely related to what tasks one can perform in society [25,31], hence, when treatment takes the patient away from performing, it is seen as a step backward in health. Treatments that make the patient sick, such as chemotherapy, are therefore deemed to be undesirable[31]. Furthermore, the holistic health framework associated with Indigenous health belief purports that spiritual, physical, and emotional factors are essential to ones' interconnected wellbeing[6,30]. This alternate view is in conflict with the biomedical position which focuses on physical health[25], thus creating the opportunity for miscommunication and misunderstanding between Indigenous patients and Western health service providers that cannot be overstated[27,32] to occur. Miscommunication can also occur due to the ethnocentric setting of the clinic, whereby the providers of care have different cultural nuances - beliefs, mannerisms, language and body language- to their patients, leading to misinterpretation by either patient or clinician.

Many Indigenous languages do not have a word for cancer, making it difficult to conceptualize[23]. This emphasizes the belief that it is a 'white man's disease' that only came about after colonization. Whether this is true or whether it was never labelled as cancer until colonization is unknown; however, many signs point to the fact

that the change in Indigenous lifestyle from traditional to Westernized has increased the risk of cancer[33].

## Methods

This project was developed in response to a need identified by health service providers for greater understanding of Aboriginal Australians' beliefs, understanding and experiences of cancer, cancer care and treatment[34]. Aboriginal people have also argued for their health needs to be better understood by the western health system. The research was approved by the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC), the Human Research Ethics Committee of Curtin University and The Royal Perth Hospital and Sir Charles Gairdner Hospital Ethics Committees. An Aboriginal Reference Group (ARG) was established, involved and consulted throughout the study period.

Inclusion criteria for the study involved Aboriginal adults who were cancer patients, survivors, family members of people with cancer or people who died from cancer who are or were intimately involved in another's cancer journey. Detailed description of the processes and methods for the study are published elsewhere[35]. In short, recruitment occurred through the networks of the researchers and reference group members, via health professionals in primary or tertiary care, through relevant

Aboriginal Health Services or other local support agencies. Thirty-seven [Demographic details are presented in Table 1] in-depth open-ended interviews were conducted with Aboriginal participants (including some Aboriginal health service providers) in Perth (urban) and in one rural and two remote areas of WA between March 2006 and September 2007. Participants included patients and family members who were diagnosed or died from different types of cancer. Most of them were diagnosed with breast cancer (N = 11) followed by lung (3), cervical (4), bowel (2), throat (2), head and neck (2), pancreas (1), leukaemia (1), ovarian (1), mesothelioma (2) and melanoma (1). All participants spoke English and gave written informed consent. However, English was not the first language for a few participants, especially those who were recruited from remote communities. Participants were asked about their experience (either in their own life or that of their family) with cancer. Interviews were audio-recorded and transcribed verbatim. Thematic analysis was undertaken where transcripts were reviewed by two researchers independently and the material read repeatedly to derive the key themes. Thematic analysis is independent of epistemology and theory providing a flexible and useful research tool which can give a detailed as well as complex description of the data[36].

## Findings

Of the thirty-seven interviews conducted, twenty-two mentioned bush medicine in some form. Many were minor references that did not encapsulate clearly the connection between bush medicine and cancer treatment. The eleven interviews that made significant mention of bush medicine (seven were prompted and four were spontaneous) are the focus for this paper; thus, the comments and themes elaborated reflect only a proportion of Aboriginal people's perspectives on this issue. The themes have been organized to explore two questions: i) what were the key factors for which Aboriginal patients chose to use bush medicine and ii) what factors influenced their decision not to use it. Subthemes are described below:

### Reasons for using bush medicine for cancer

Respondents who mentioned using bush medicines saw it as a preventive means to cope with the stress of cancer and believed that the healing powers could help to cure and relieve the anxiety and conditions of cancer.

#### **Relieves stress: "... it gets rid of all your internal stress"**

The belief that stress can cause cancer was brought up by many of the respondents. The views of a number of participants were encapsulated in a comment by one participant who saw cancer arising as a flow on effect of the disruption and stress following colonisation:

*"One minute, Aboriginal people had land and [then the] 1905 Act... see all those land taken away. ...so, that causes a lot of stress... the stolen generation... stress. We know... people were in stress and depression... that sort of things can cause cancer."* [Urban male participant]

Related to this was the idea that bush medicine reduces the risk of cancer. Bush medicine was regarded as a preventive measure as it helped to release stress, making the person stronger from the inside:

*"What happens is... it's a bush... or root... that you boil it up... and... it's a browny... it's got like a bark taste like a woody taste... But there is something in it... that is good for insides, just as a cleanser. Makes all your body organs healthy and strong, it gets rid of all your internal stress."* [Urban male participant]

Another participant talked about maintaining her long-standing belief in bush medicine and using it even after being diagnosed with cancer. She explained that a great deal of Aboriginal people were naive about cancer and got stressed when they heard the diagnosis. From others' stories it was clear that, to them, bush medicine could help in releasing the burden of their illness.

The 2002 National Aboriginal and Torres Strait Islanders Social Survey showed that Aboriginal people over the age of 18 were 1.5 times more likely to have reported experiencing a life stressor. Lurking in the collective memory of Aboriginal Australians is the legacy of child removal (the "stolen generation") and other historical mistreatments experienced in their recent past with its devastating effect on cultural practices and living conditions, including creating barriers to the development of social capital within Aboriginal communities[37].

#### **A connection to spirituality and holistic health worldview: "Healing is mental, emotional and spiritual as well"**

For some of the participants the application of bush medicine was not only seen as relieving stress but was also seen as an enabler in maintaining their connections and beliefs on culture, ancestors and spirituality. The practice of bush medicines confirmed and supported participant's cultural beliefs and attitudes that conformed to Aboriginal understandings and epistemologies of health and wellbeing as holistic. Engaging with bush medicines and the associated healing rituals that accompany its use is spiritually significant to Aboriginal people whose identity and connection is embedded in their relationship to the land. The relationship that Aboriginal people have with the land is sacred and related to their concept of health, wellbeing and healing[27]. Two excerpts clearly illustrate this connection:

*"Yeah, their spirituality is always there; they link bush medicine with the land, but it is very hard to get, because there's not many people who go out and get it. You get it from certain trees and what-have-you. But*



*that belief that trying bush medicine will heal them is still there.*" [Urban female participant]

Consistent with several other interviewees, this participant would not go into particular detail about where you can get bush medicine and what it is. This keeps the spiritual mysticism alive.

*"An old lady came up there with a bottle. I said, I can't eat for six months... can't swallow anything. She said, 'You drink it, and you would get better.' And I believed that. And it's gone. I went back for the check-up, and the doctors asked me, 'Hey, what did you do? It's not there. What did you do? Did you see someone special?' I said, 'Yes, there was this old black lady. She pushed me to drink. And I had it.' He said, 'Bring that to me.' He wanted to know the secret. No, you can't. You have to get it from that old lady. It belongs to her. I hadn't got it. She had got it. So, I asked to the lady, and she said, 'It belongs to the land. Leave it where it is.' That's the way life is. If you want anything, you go and ask for it."* [Remote male participant]

For this participant, the spirituality associated with healing comes from and belongs to the land. To relinquish the bush medicine to the doctor would be subjecting it to a western medicalised inquiry that conflicts with that spirituality and with the holistic health worldview. The patient wanted to maintain the sacredness of his relationship with the country and its spirits. It could also be about protecting Aboriginal knowledge from appropriation by the western system which in the past has been highly exploitive. The old lady's response was a recognition of cultural protocols and affirmation of ownership in that, she did not have the authority to pass on the information. This highlights the tension between what is allowed to be public knowledge by Aboriginal people and what remains private.

Healing and the holistic health worldview were stressed several times, particularly by two interviewees who worked in health care. One of them emphasised that *'healing isn't just a physical thing'* rather it is very much related to patients' *'mental, emotional and spiritual'* state. This worker firmly believed that sometimes miracles do happen in life, and people could recover, even from serious illnesses like cancer. As one female participant who worked in an urban Aboriginal medical organization stated: *"the spirit world is an integral part of day-to-day life; yes, absolutely"*. The allusion to 'miracles' by the first respondent also supports the idea that bush medicine is spiritually-based. These participants reinforced the need to cater to the spirituality of Aboriginal patients as part of the healing process.

Many participants generally argued for accepting and communicating about the use of bush medicine with Aboriginal patients in their cancer treatment plan concurrently with western medicine. One participant who

was a medicine-man expressed his feeling about someone benefitting from his medicine: *"if it worked... if either one (white-men medicine or the black-men medicine) that is good because it gives you a chance"*. To help in this way confirmed the man's healing ability, establishing his identity and status in the Aboriginal community as a healer and validating Aboriginal knowledge as having a legitimate place alongside western medical approaches. He also stated that he did not take money for bush medicine as he believed his ancestors would not approve, demonstrating his deep spiritual respect for his ancestral relations, a recurring theme in Aboriginal communities. Participants commonly noted that believing in the effectiveness of bush medicine is important: described by one participant as *"pure positive thinking"*. Another participant clarified that bush medicine and western medicine were not incompatible:

*"a lot of people say, 'Oh, yeah, that's just a lot of rubbish' and especially you will find doctors that say so...No, I'd never say, 'Discard conventional medicine and just concentrate solely on this', because I think it's got to complement each other, and if you've got those beliefs already... that this is gonna help you, it will (emphasizing). It may not cure you. It may not save your life, but it will help you, even if it's only in a mental or an emotional way of help. So, I really do believe that it would help, and have just having somebody there to go and smoke the house... to get rid of all the bad feelings. I mean that's ... a lot of these are very spiritual stuff that Aboriginal people have known for millennia,"* [Urban female participant]

Bush medicines and traditional healing approaches are compatible with other complementary, alternative and integrative medicines, of which the use is increasing among patients with cancer, with the average prevalence rate of 31.4 percent in the Australian population[38]. This underscores the need for complementary therapies such as bush medicines and spiritual healing to be discussed with all patients undergoing cancer treatment. This was put into the context of ancient cultures by one participant:

*"Chinese have been practicing all this acupuncture, acupressure and all those sorts of things for thousands of years, and now it's all in vogue, so it's all right. It's the same thing with the bush medicines. Even meditation! and all these things. They are all of a sudden miraculously, 'Yes, they do work.' Well a lot of Aboriginal people, and old cultures have known that for so... long."* [Urban female participant]

As the Indigenous concept of wellness and hence healing is linked to their culture and spirituality, there is a need for health care providers to acknowledge and respect this component of Indigenous beliefs when providing health care.

**Adverse reaction from biomedicine: "Radiation and chemo nearly killed me"**

*"I know a couple of people who chose the bush medicine once they read up about chemotherapy and the two per cent of people that chemo cured, they took their chances with the bush medicine, and they are still going. It's either the quality of life or being sick from the chemo, that's what they weighed up."* [Rural female participant]

There are some Aboriginal people who use traditional medicine as an alternative to Western medicine. Both cancer patients and the family members felt some people get scared about the intensive procedures of common cancer treatments and their side-effects, influencing them to choose other options instead. As well, some patients did not cope with the side-effects of chemotherapy and radiation treatment and disliked having to spend long periods away from their family and home town. This was made more salient for Aboriginal women if they had the responsibility of taking care of their children and grandchildren, impacting on the choices made between using traditional healing and medicine so that they did not have to go away. One respondent summarized:

*"It's hard for a lot of people. So, they prefer to either go for bush medicine or not take the treatment, because they know that they are going to be away for a while from their family."*

The perception of some of the participants towards bush medicine was how well people were when they were taking it: *"She looked better when she took the bush medicine"*. These perceptions confirmed and validated the healing qualities of bush medicine as an alternative or as a complementary approach to Western medicine.

**Last resort and desperation to try everything: "at the end we were just clutching to hope"**

One urban female participant shared the story of her young relative who had died of cancer. The patient kept faith with the Western doctors, hoping that they were going to fix the cancer and seeing them as 'miracle-makers'. However, when everything failed the family turned back to their traditional treatment which by then was too late as the cancer had advanced too far. After sharing her story, the participant admitted that *"really, they (doctors) are not miracle-makers and, we've got to start doing some stuff, too."* Attempting a range of different healing options to treat cancer, especially when Western medical treatments have not worked are not uncommon in many societies[39,40] and is another reason why some people turn to alternative medicine.

Having cancer caused fear and was often associated with fatalism about the likely consequences. Upon diagnosis, many people started thinking immediately about death and consequently panicked. This fear prompts

them to desperately try everything to cure the disease. One participant said:

*"I would try different treatments. I would try what I have heard works. I would definitely try the hospital, what they had to offer. I would try... if I had heard of a good bush medicine that could fix it, I would try that. Ye.., I wouldn't be hesitant in using alternative medicines at all, whether it be from the Aboriginal bush medicine or from somewhere else."* [Urban female participant]

Although this participant reported not knowing much about bush medicine because she grew up in urban areas, she said she would give anything a go if somebody said that it could work.

**Reasons why bush medicine was not used**

Many respondents did not use bush medicine or did not talk about the use of bush medicine during the interviews. For many, it was not because they did not want to use bush medicine, but rather that they did not have access to the source, got confused about what would be better for them to use, or were unsure about the process of taking it.

**Not easy to get**

Many participants, especially Aboriginal people who lived in the city and in the rural towns admitted that it was hard to get bush medicine, as most traditional healers lived in rural and remote areas. This meant that they either had to travel away from where they lived or organise for the traditional healer and supplier of bush medicine to travel to where they lived; both a time-consuming and expensive exercise. These issues restricted their choice of using bush medicine. Some people also explained that although they wanted to use bush medicine, they did not know who, how and where to contact a traditional healer.

One participant when asked if they had taken any bush medicine replied:

*"No, no. No, I haven't had any. No, I got to go up to Wiluna and get some."* [Rural female participant]

It should be noted here that a healer has to be authorized to be able to practice and prescribe bush medicine. As one participant described:

*"The 'ok' to use it. You just can't go and use it. He told me that I could go ahead and get the medicine, and prepare them, and use it. Otherwise, in our ways, you can't just use it unless anybody given the 'ok' to you to use it. So, he gave me the 'ok' to use it."* [Urban female participant]

Being given the authority to collect the plant used for treating cancer also involved being trusted enough to be told where to harvest it, how to prepare the medicine and how and when to take it. For this to happen requires that

the person has a good relationship with the healer, who would not hand over his/her knowledge over lightly.

**Urbanized Aboriginal people: "... we are urban Aboriginal, we are not traditional"**

A devastating effect of colonisation was the alienation and disconnection of Aboriginal people from their land, their cultural heritage and traditions. Being taken away from their family and raised elsewhere on missions or placed in non-Aboriginal families was traumatic for those who were removed. The separation from their traditional country and families and the relocation to urban and regional centres meant that for some there was a loss of cultural knowledge, language and tradition. Some respondents admitted that they had lost their connection with their traditions and culture, while others said that they continued to visit their homeland occasionally, for funerals or other ceremonies. Participants who grew up in Western society and had been exposed to Western education had access to modern technologies and information systems and a reasonable knowledge of the cancer that troubled their family member. Many of these people did not try to look for bush medicine and traditional healing. As one of the participants said:

*"We were born into ... a society that were fully functional at that time... we are urban Aboriginal, we are not traditional. We have access to information, technology, whatever. We didn't have any Aboriginal remedies... or anything like that..."* [Urban female participant]

However, not all urban Aboriginal people subscribed to this view. Traditional beliefs and practices persist amongst many urban Aboriginal people and may become visible only when it affects those who are close[41]. 18 participants reported that they had connections with some traditional practices, but not in a very strong way. For example, use of bush medicines was one thing some of the families were practicing despite limited knowledge and access to other traditional healing practices.

Another reason given by some participants for foregoing traditional practices was religious beliefs. Christianity was imposed as part of the colonizing process and with this came restrictions upon Aboriginal peoples' life-style and values system[41]. Many Aboriginal people were exposed to Christianity within the missions, places where they were forced to leave their Aboriginal beliefs, culture and traditional rituals behind. Those directly affected by missions and subsequent generations, who have grown up in a "Christian" environment, may regard traditional Aboriginal beliefs as akin to paganism and thus discourage their use. In the words of one participant:

*"We didn't use traditional medicine or anything like that. Because we are not traditional Aboriginal, and our family was Christian based, and so...We put our trust on God."* [Urban female participant]

**Dilemma of usage: "I was a bit worried taking any of that..."**

Secrecy and mystery abound in the Aboriginal community about the use and availability of bush medicine. This inevitably means poor availability of accurate information regarding its actual use. As Western medicines usually have detailed prescriptive and side effect information available, this created an expectation among some Aboriginal people for similar processes and information being available for bush medicine. As one participant said:

*"I was a bit worried taking any of that because none of them could tell me exactly how much, what quantity to take and I was worried about that..."* [Rural female participant]

Another participant from the rural area said that she tried bush medicine but had severe reactions (rash and urine infections) so she stopped it. She wanted to just stay on bush medicine provided more accurate information and guidance was given to her. The conflict between the use of western and traditional healing meant patients had to make choices, presumably based upon their relative confidence in what each treatment would offer: *"I tried [bush medicine], but, yeah, I think it reacts with all my tablets I'm taking."*

## Discussion and Conclusions

There has been little study of the role of bush medicine and other traditional healing in contemporary Aboriginal society in Australia, and very little about the use of traditional medicine in cancer treatment: what information is available is anecdotal. The desire to use traditional medicines among Aboriginal patients is still widespread, even for a serious disease like cancer. Aboriginal participants in the study acknowledged traditional healing practices and use of bush medicines as important aspects of cancer treatment. Bush medicine has spiritual significance for Aboriginal people as it is natural, comes from the land, connects to identity and spirituality and plays an important role in people's health and wellbeing. Bush medicine is also connected to the holistic world view in such a way that the interplay between the physical, emotional, social and spiritual aspects is crucial in attaining wellbeing. Whereas hospitals and Western medical systems are representative of the dominant society reminding Aboriginal people of their loss of cultural knowledge, access to the traditional healing system, bush medicine and other healing processes repairs some of the damage inflicted by colonisation. The opportunity to access traditional knowledge through other groups who have retained this knowledge can be reassuring for Aboriginal people with cancer.

People often turn to spirituality in dire situations, and this is the same for cancer which is often regarded as a

death sentence[24]. Aboriginal people with cancer who were at the end-of-their life phase and were away from their home indicated that they wanted to go home. On returning to their home they then incorporated bush medicine and other traditional healing processes into their treatment. Findings from the study revealed that the use of alternative medicines and approaches in cancer treatment often brought comfort and peace to the patient. Unlike Western medical treatments, traditional healing is embedded in holism and challenges the biomedical system that Aboriginal patients have to deal with. The use of traditional medicines and healing can empower patients in the health process, creating possibilities for positive outcomes.

This study revealed that in Aboriginal communities the cause of cancer is attributed to a number of different things; stress and/or the influence and impact of the dominant culture and sometimes cultural causes. It is often interpreted as a "white-man's disease" and linked to colonisation. These factors can create a hesitation to use bush medicine because of the pressure and expectation to engage with the dominant health system and the well-established biomedical model. On the other hand, bush medicine is considered culturally safe, a practice connected to Aboriginal ways of being and doing. Applying bush medicine and engaging with an Aboriginal healer provides comfort from a cultural perspective that is healthy and healing for the spirit. This explains why some Aboriginal Australians see bush medicine as a non-stressful alternative treatment for a disease that may be attributed to stress.

For health care providers, it is important that they have an appreciation and understanding of Indigenous belief systems in relation to health care, and work to incorporate this understanding into their service delivery. One way to do this would be to adopt a family-centred, integrative approach that works with the individual in concert with their familial and cultural support. Applying this type of approach not only respects Aboriginal people's choice to utilize bush medicine as a part or whole of cancer treatment and their overall search for health and wellbeing, but recognizes and begins the journey of working with Indigenous epistemology and ways of doing.

It is also of value for practitioners to know that their patients are taking bush medicine because there can be potential risks involved in using both. Plants, leaves and trees used in making bush medicines may be bioactive and can have physiological, emotional and psychological effects. A well-known example of a herbal drug that interacts with biomedicines is St. John's Wort, *Hypericum perforatum*, which is a traditional European herbal drug used to treat mild depression that interacts with a wide number of biomedicines, including anti-retroviral drugs, oral contraceptives and warfarin[42].

Another risk that medicinal plants may pose is that they often may not be safe to use. Effects may not be immediate, and the potential toxicity of plants may be hidden to traditional healers. Many of the plants used traditionally by Aboriginal people in Australia have not been studied phytochemically, thus this is an unknown area. Thus, acceptability and understanding of the use of these medicines would provide a rationale for dealing with such issues. Further exploration of these issues may be needed but this needs to start with clinicians being alert to the possibility of use of bioactive agents that are not prescribed.

Recognition and understanding of the use of traditional medicine and healing system can boost the confidence of Aboriginal people to access mainstream services and it will definitely improve the delivery of health services to Aboriginal communities. Both medicine needs to be supported and developed with enduring research so that the therapeutic value of traditional medicine can be judged and understood. The growing popularity and use of complementary and alternative medicine world-wide may assist and support the improvement and sustainability of Aboriginal Traditional medicine and healing in Australia.

#### Competing interests

The authors declare that they have no competing interests.

#### Authors' contributions

SS participated in the project's design, carried out the data collection and analysis for this project, prepared the initial draft. RB contributed to preparing the initial draft and commented upon drafts of the manuscript. DB was involved in writing and commented upon drafts of the manuscript. SCT coordinated the whole project, participated in the design and assisted with the conduct of the study and writing. All authors read and approved the final manuscript.

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**CHAPTER SEVEN**  
**General Discussion**

## 7.1 Introduction

This PhD research was conceptualized and developed while the researcher was involved in the project entitled “Improving Cancer-related Services for Aboriginal People: Possible Roles for the Cancer Council Western Australia”. The project included undertaking an environmental scan of existing and past programmes and practice in Indigenous cancer control by member organisations of The Cancer Council Australia. A comprehensive literature review was undertaken as part of that project, identifying and critically analysing both peer reviewed and grey literature on epidemiological data and cancer-related initiatives among the Indigenous populations of Australia, Canada, New Zealand and the United States of America (USA). The aim of the review was to:

- identify the strengths and gaps in the literature
- identify the key issues and understand the pattern and risk factors of cancer among Indigenous populations in those four countries
- identify the approaches adopted to deal with this health problem, particularly successful approaches to increasing engagement with cancer issues and cancer control among Indigenous populations.

The literature review identified that limited information was available regarding cancer among Aboriginal Australians (Condon et al. 2003; Cunningham et al. 2008; Roder 2007; Valery et al. 2006). The lack of attention given to this issue had generated an erroneous impression that cancer did not have a great impact on the Aboriginal population (Thompson, Shahid, and Beckman 2006).

However, Canada and the USA had recognised the need for in-depth understanding of Indigenous people’s beliefs about cancer and their needs with regard to cancer treatment and care as defined by them (Aboriginal Cancer Care Unit 2002; Burhansstipanov 1999, 2001; Burhansstipanov et al. 2001). As the literature review has shown, few recent publications from Australia have identified that understanding and acknowledging differences in the perceptions, needs and preferences of Aboriginal people is critical to engaging them better with the services (McGrath et al. 2006; Prior 2009). Moreover, barriers to accessing cancer care services had been

identified in the other three countries (New Zealand Health Strategy 2001; Burhansstipanov et al. 2001; Aboriginal Cancer Care Unit 2002) but not in Australia. Identifying the barriers had led to recommendations and strategies had been adopted accordingly. Individual views and experiences regarding cancer and cancer services and their effect on people's care-seeking behaviour were prioritised in each country, and diversified beliefs and attitudes were explored through research at various levels (New Zealand Health Strategy 2001; Thompson, Shahid, and Beckman 2006; Aboriginal Cancer Care Unit 2002; Shahid, Beckmann, and Thompson 2008; Walker et al. 2008). When this current study was started, Australia was far behind the other countries with regard to cancer research and services for its Indigenous population.

The environmental scan also identified that there was a pressing need to better understand the range of issues that lie behind Aboriginal cancer disparities and to direct efforts at changes to improve the situation (Shahid, Beckmann, and Thompson 2008). There has been an increasing recognition and acceptance that health sciences research in multicultural settings should employ qualitative research methodology to capture accurate and in-depth information on sensitive topics (Denzin and Lincoln 2005). As part of the research undertaken exploring possible roles for Cancer Council WA, interviews with staff had identified that they recognised the need to be doing more in Indigenous cancer control, and were keen to do more and do better. Some were aware of their ignorance about Aboriginal people and particularly wanted more understanding of the socio-cultural perspective of Aboriginal people with cancer; others defended their practices by saying "we treat everyone exactly the same".

This need and the dearth of published research in the area from Australia at that time led to the development of the research described in this thesis. A phenomenological research design was employed to understand and explore the beliefs, understanding and perspectives around cancer of Aboriginal people in WA. It was recognised that only by these needs being identified, understood and acted upon, and the real and perceived barriers removed, would individuals be encouraged to present earlier and Aboriginal cancer outcomes improved. A change in approach and in service delivery



was required for screening or assessment to occur early enough and for those affected to engage in treatment. Ultimately, through the research it was hoped to find information that could be used by policy makers, service providers and planners to improve mainstream services to meet the needs of Aboriginal people.

## **7.2 Overview of the study findings**

Some of the key findings from the research are summarized below.

One key research question was whether beliefs and understanding of cancer contribute in any way to Aboriginal people's decision-making process around accessing cancer treatment services. Findings from this exploratory research are summarized in the following few paragraphs.

Beliefs, views and attitudes have been found to have profound implications for peoples' receptiveness to, and participation in, prevention, early-diagnosis and treatment programmes (Germov 2005; Aboriginal Cancer Care Unit 2002, 2002). Burhansstipanov (2001) highlighted some cultural issues that hinder early detection and treatment of cancer among Native Americans (Burhansstipanov 2001; Shahid and Thompson 2009). Prior (2005 and 2009) and McGrath and colleagues (2006) also identified that Aboriginal people sometimes keep their cancer diagnosis secret due to the cultural belief of "bad spirits", sorcery and payback (McGrath et al. 2006; Prior 2005, 2009).

Similar findings were obtained from this study. A pessimistic attitude about cancer as a 'killer' was very common among the research participants and this affected their decision to access services from initial presentation with symptoms, diagnosis, treatment, through to follow-up after treatment. Most of the participants, irrespective of rural, remote and urban residence, had limited understanding that progression of cancer can be slowed or even cured with timely Western medical treatment. Shame and fear attributed to cancer often made people reluctant to talk about cancer and their symptoms (Prior 2005; Shahid, Finn et al. 2009). Consequently cancer is often diagnosed at an advanced stage, and hence there are low survival rates among

Aboriginal patients with cancer. This poor survival rate reinforces the negative perceptions of cancer, and the shame associated with the disease means few positive stories of surviving the disease are disseminated in the community.

Stigma and shame attached to cancer diagnosis was reported for participants from urban, rural and remote areas alike. Some people had an underlying belief that cancer is contagious and this can result in cancer patients being isolated from their communities and deprived of the help they need from their family and friends (Shahid, Finn et al. 2009). Similar findings were obtained from a study conducted in Northern Territory (McGrath et al. 2006).

Traditional and mystical beliefs about the cause and implications of having cancer are widespread among Aboriginal people. Cancer, like many other diseases, is associated with the spiritual world of curse and payback, and these impacts upon people's choice of cancer services. The concept of wholeness and balance in good health and well-being incorporates the essential belief that the physical, mental, spiritual and emotional aspects of life are connected and cannot be separated. This is fundamental to many Indigenous beliefs (Aboriginal Cancer Care Unit 2002) and affects all aspects of decision-making and cancer management among Aboriginal Australians. Mainstream services, by not acknowledging or addressing such alternative perspectives on health and treatment, can often contribute to a general attitude of mistrust and pessimism which is common among Aboriginal patients. Close to half (n=18) of the Aboriginal participants in this study mentioned use of bush medicine and traditional healing concurrently or as an alternative to Western medicine and treatment for cancer. Although cancer has been conceptualized as a "Western" disease (Aboriginal Cancer Care Unit 2002; Prior 2005; Burhansstipanov, Lovato, and Krebs 1999), traditional treatment alternatives are still preferable to many Aboriginal people (Shahid, Finn et al. 2009).

This study also found that a lack of knowledge and understanding about symptoms of cancer was another major contributor to Aboriginal people delaying seeking health care in response to symptoms, or being dissatisfied and non-adherent with their

cancer treatment. Some people did not understand what they were being told by their doctors and specialists about the treatment, the requirements and possible outcomes from treatment, the importance of follow-up after treatment, and so on. It was often reported by participants that Aboriginal people lacked appropriate support during their post-operative recovery phase; did not get adequate and appropriate information from the hospitals; and did not have experience and knowledge about how they could manage their daily life after treatment. All these contributed to many Aboriginal patients and their families reporting that they felt uncomfortable and uncertain while using mainstream cancer services and treatment options. This also contributed to developing distrust towards the system which did not meet their needs (Shahid, Finn, and Thompson 2009; Shahid, Finn et al. 2009).

A second question for this research related to understanding the practical barriers and experiences of Aboriginal people in accessing treatment and cancer services.

Effective communication and understanding between patients and health care providers is critical for quality health care delivery, patient satisfaction and effective treatment (Cooper and Roter 2003). Miscommunication between service providers and Aboriginal clients was identified as one of the major barriers to Aboriginal people's access to mainstream health services. Several impediments to effective communication between Aboriginal patients and health care providers were identified (Shahid, Finn, and Thompson 2009). One study from New Zealand has also identified similar issues to this study, with miscommunication an issue in Maori patients' and survivors' cancer journeys (Walker et al. 2008).

Distrust stemming from past experiences of colonisation, negative experiences within hospitals, dispossession of lands and destruction of culture, and racism also impede some Aboriginal people from relying upon the Western medical system and doctors. Participants' views were often shaped by recollections of previous personal and collective experiences (Shahid, Finn, and Thompson 2009; Walker et al. 2008). They shared stories of times when they were discriminated against while accessing services, and when Aboriginal people had died when they were turned away from hospitals or were not given the right treatment. This history was carried over into

interactions with health service providers, and resulted in mistrust of mainstream services.

‘Logistical and infrastructure barriers’ was a major theme that emerged from the interviews and was identified as another hurdle for Aboriginal people to overcome to access mainstream health and cancer services. Outcomes described relate specifically to the basic whole-of-treatment infrastructure which governs the treatment experience for rural and remote dwelling Aboriginal patients. This includes transport and accommodation arrangements, hospital environment and infrastructure and Aboriginal support/liaison across these basic necessities. Issues relating to expense of treatment and medication were also mentioned (Shahid, Finn et al. 2009).

Lack of culturally competent support services within the hospital setting is a crucial barrier. During this research, it was found that no interpreter service for Aboriginal languages was available within the tertiary hospitals that treat cancer. There was an inadequate number of Aboriginal Liaison Officers (ALO) to help patients to feel more informed and comfortable about the whole cancer treatment process. Patients often arrived at the hospital completely unprepared for the experience, lacking basic necessities such as money to purchase food and clothing suitable for the climate in Perth. Participants identified that if Aboriginal patients were aware in advance of what was going to happen and the likely length of stay in the hospital, they could be better physically and mentally prepared. Aboriginal cancer patients need psychosocial support – an Aboriginal Health Worker, a counsellor or social worker who can sit and listen to them and source appropriate help for any issues raised. Although many of the issues identified are applicable to non-Aboriginal people as well, the extent of the impact on Aboriginal people is compounded by other factors including their collective historical experience, cultural background, needs and preferences, and poorer socioeconomic circumstances.

Participants in this research emphasized culturally sensitive interpersonal contact between a patient and a provider. Aboriginal patients and their family members wanted an ongoing, trusting and warm relationship with a provider. To them, good

care must encompass relational issues such as being treated with dignity and respect and being given a say in decisions that affect their life. Opportunities to have family around at a time of fear and stress to provide familiarity and support were paramount. Acknowledgement and understanding that all Aboriginal people are not the same and respect for the importance of land and community to Aboriginal patients were also reiterated in the comments of many participants. This perspective conforms to the principles of cultural studies which often concentrate on how a particular phenomenon relates to matters of ideology, nationality, ethnicity, social class and gender (Serrat 2008).

### **7.3 Limitations of the research**

This study initially proposed to look at the experiences of Aboriginal people and of the health service providers who are involved in providing care following diagnosis of cancer. To gain insight into the experiences of Aboriginal cancer patients, both survivors and/or family members of a person who had died from cancer were interviewed. These interviews form the subject of this thesis. The other group which can provide important insights are the health service providers, but due to time constraints and the interest from the stakeholders regarding the views and beliefs of Aboriginal Australians on cancer, the interviews with health service providers remain substantially unanalysed and are not included in the publications to date or in this thesis. Health service providers' views and perspectives on their experiences in dealing with Aboriginal patients will be analysed and reported in further publications. Suffice to say at this point that the views and insights of those interviewed varied considerably.

The ideas that formed the basis of this research were submitted as a grant application to the National Health and Medical Research Council and Cancer Council competitive grants by my supervisor and colleagues over two years. Fortunately, the proposal received a \$60,000 grant in one year, but despite the efforts of the researchers, funding was not secured beyond one year. Thus funding fell well short of what would have enabled the research process to engage fully and intensively with the Aboriginal communities that assisted with the research. In particular, this has

restricted opportunities to provide optimal feedback to participants and Aboriginal communities and for optimal research translation. Furthermore, the researchers have not had the resources to provide and seek personal feedback to and from the study participants. However, I have presented these findings to many Aboriginal community representative forums organized by other organisations and obtained feedback from the attendees. In addition, my supervisor and I have presented the findings to various Aboriginal and non-Aboriginal organisations and health service providers to increase their understanding about issues related to Aboriginal people with cancer. We have continued to engage in advocacy and sharing knowledge about Indigenous cancer issues. Copies of the interviews were sent to some participants and other organisations are utilising the study findings and the information voiced by participants to inform their activities. This has been done with care not to breach the confidentiality of the participants.

Men were under-represented among the participants of this study. Contributing factors could be that the key interviewer was female; the predominance of women among the Aboriginal Reference Group (ARG) members and in the community-based health workforce; that women utilize health services and seek help for their sicknesses more often than men; or, because men have more aggressive cancers, present later and there are fewer male survivors of cancer. Funding constraints meant it was not possible to employ a male interviewer during the interview phase, in spite of the researchers recognising and acknowledging there may be sensitivity for some Aboriginal men in talking about cancer with a non-Aboriginal female interviewer. We had no evidence that men had cultural constraints that proscribed their participation in the research although this may be another explanation for the lower number of male participants.

Issues of language may also have impeded both the interviews and their interpretation. As the primary interviewer, I undertook all interviews in English. Even if there had been funding to pay Aboriginal interpreters, the lack of professional interpreters would have posed a problem in small communities. The criterion that participants had to speak and understand English means that the views

and experiences of more traditional Aboriginal people, for whom English may be a third or fourth language, are missing from the data and the analysis.

This study required time to consult Aboriginal stakeholders before Ethics Committee approval was obtained. It then took eighteen months to undertake the data collection. Building relationships, trust and linkages with communities were prerequisites to conducting interviews in the community setting, all of which took time. The imperative to provide feedback and ensure that the information gained was used to inform services and system improvements for Aboriginal people meant that these “responsibilities” all delayed completion of this thesis. As a researcher, I was torn between my desire to complete the thesis and my obligations to the participants to ensure that their stories could ultimately make a difference and inform service planning. The difficulties of undertaking collaborative research from an academic environment have been described by MacLean and colleagues (MacLean, Warr, and Pyett 2009) and are challenges that I came to understand well. Issues such as the time-consuming process of consultation and negotiation with several stakeholders, difficulties securing funding for community-oriented qualitative research, uncertainty around appropriate and adequate information provided to stakeholders and to communities; and the requirements to publish in academic journals and so on are well-known issues which influenced and impacted upon the progress of this research. Members of the Aboriginal community, understandably, do not generally appreciate the requirements of academic research and nor does the academy fully understand the obligations and time consuming nature of undertaking research with Aboriginal communities.

Finally, this research was undertaken in a number of communities in Western Australia. There is tremendous diversity in Aboriginal communities and even within the one community and the beliefs and experiences of individuals are likely to be quite heterogeneous. Hence, caution needs to be exercised in interpreting the research findings in terms of their applicability to the views of Aboriginal people throughout Australia or even WA. However, the views expressed by the participants in this study overlapped in many areas with those of the few other published studies

within Australia (Lowenthal, Grogan, and Kerrins 2005; McGrath 2000; Toussaint, Mak, and Straton 1998; McGrath et al. 2006; Prior 2005; Prior 2006; Prior 2009) and even those of Indigenous people in other developed countries (Burhansstipanov 2001; Aboriginal Cancer Care Unit 2002; Burhansstipanov, Lovato, and Krebs 1999; Shahid and Thompson 2009; Walker et al. 2008).

#### **7.4 Research outcomes and directions for future research**

This project identified several gaps in knowledge and understanding about cancer and cancer services by Aboriginal people, and a lack of support services within Aboriginal communities and in cancer treatment services. These create barriers for Aboriginal patients to access treatment during their cancer journey.

A very positive offshoot from the project was identifying an Aboriginal woman, Annie Pepper, who initially worked as a cultural consultant to support research interviews with participants in the Geraldton area. Listening to a number of participants describe their own experiences resonated with the experience of losing her own father to cancer. With support from the project, she was able to obtain a six month Aboriginal and Torres Strait Islander health promotion scholarship and worked in the Geraldton area on cancer issues. Within that project she catalysed local Indigenous women to establish the Midwest Indigenous Women's Cancer Support Group (IWCSG). The IWCSG worked to raise the awareness of cancer in local Aboriginal people, for example at 'National Aborigines and Islanders Day Observance Committee' (NAIDOC) week. The Group has continued to spread messages related to cancer, forge linkages with local health service providers and advocate on behalf of Aboriginal people in both rural and urban communities on cancer issues and support. Based in Geraldton, the Indigenous Women's Cancer Support Group has been operating to disseminate information in a relevant and accessible manner, build on the sense of community to provide personal support to individuals with cancer and improve knowledge about and attitudes towards cancer and health treatments (Finn et al. 2008). This initiative provides an example of an approach that could be useful in engaging Aboriginal people in issues related to cancer in other regions. To ensure that the voices of Aboriginal consumers are heeded



in implementing changes to cancer prevention and treatment services, a community-based participatory action research approach should be adopted. The group receives ongoing support from the Centre for International Health at Curtin University and efforts to obtain more secure funding for the work of the group continue. Further documentation of the work of the group is planned, and other research has been undertaken and is planned in conjunction with them.

Capacity building and reciprocity are important aspects of undertaking research with Aboriginal people. I have provided information to Aboriginal people for use in their own work and presentations. I have encouraged Aboriginal people to be co-presenters during presentations in the conferences, forums, seminars and lectures. In particular, I often co-presented with Leanne Pilkington, the dynamic and committed Indigenous programme officer who has worked for several years at BreastScreen WA. Leanne has been awarded an Indigenous Research Training Scholarship from Healthway and in 2010 she will begin a Masters by Research at the Centre for International Health to explore questions that have arisen in the course of her own work with Aboriginal women. Aboriginal researchers are co-authors on some publications arising from this study. This has, both directly and indirectly, contributed to Aboriginal capacity-building.

Based on the recommendations from the initial report to Cancer Council WA including findings from the environmental scan, Cancer Council WA has adapted a cancer education course developed originally in Queensland and delivered it three times for Aboriginal health professionals. This course aims to increase the cancer knowledge of participants by providing practical information about cancer, treatment and the impact of the disease. The course in Perth has included visits to local cancer treatment facilities, aimed at demystifying cancer treatment and improving the care of Aboriginal people with cancer (Cancer Council WA, 2009). A full-time Indigenous Project Officer has also been appointed to improve advocacy and capacity to support Aboriginal patients with cancer in WA in a more culturally-appropriate way, and to increase the focus within the organisation on Aboriginal issues and the importance of cultural security. The Indigenous Project Officer and

other Indigenous health workers working in different government and non-government organisations in the metropolitan Perth area have recently formed a group called Women in Partnership. They have been working as a team across common issues (e.g., nutrition, physical activity, screening), performing the critical task of promoting health awareness and education among Aboriginal stakeholders. The group provides peer support for Aboriginal people who are often the sole Aboriginal position in a large organisation. By joining forces, the women are able to plan collaboratively, pool resources, cover more diseases and do much more than they could do individually working on their own.

Highlighted earlier was the under-representation of male Aboriginal participants directly reporting their views and experiences with cancer and cancer services. This thesis does not adequately explore the issues of males and this is an area for future research, best led by male researchers.

Deficiencies in Aboriginal identification and the small size of the Aboriginal population have precluded large-scale epidemiological studies of Aboriginal cancer outcomes in Australia, although the work of Condon and colleagues in the NT and Coory/Valery in Queensland have greatly enhanced our understanding of poor outcomes from cancer (Condon et al. 2004; Condon et al. 2003; Valery et al. 2006; Cunningham et al. 2008; Coory et al. 2008). Both quantitative and qualitative information is required to understand the extent and the severity of issues identified in this study. However, it is already clear that action to improve cancer-related service delivery is required, and the research described in this thesis provides suggestions for policy makers and planners on possible ways forward. Analysis of the interviews with health service providers will also provide important insights into problems and solutions with respect to these issues.

## **7.5 Conclusions and Recommendations**

It is evident from the literature that for Aboriginal Australians, cancer diagnosis of occurs at a later stage of disease, often when the cancer is very advanced. The unwillingness of Aboriginal people to participate in mainstream cancer services and

their reluctance to continue cancer treatment have been reported repeatedly (Condon et al. 2004; Condon et al. 2003; Valery et al. 2006; Cunningham et al. 2008; Coory et al. 2008; Morgan and Slade 1997). Insights into Aboriginal people's psycho-social and cultural beliefs and perceptions about cancer and its impact on care-seeking behaviour explored in this study have assisted in understanding some of the key determinants that influence their decision-making about accessing cancer treatment and other services.

It should be noted that many of the issues identified - such as distrust, exclusion and alienation actually go beyond the spectrum of narrow definitions of culture and are embedded in the broader context of social relations and network. They have applicability to many health conditions, not exclusively to cancer. A broad perspective on 'culture', encompassing attention to power relations and to historical, social, economic, and political relationships and processes is needed to understand Aboriginal viewpoints and health-seeking behaviour. The tools to facilitate Aboriginal entry into the current medical system, and then to manage effective treatment within it will require:

- culturally sensitive empathetic person-to-person contact
- infrastructural and institutional support to involve Aboriginal families within the treatment domain
- a respect for the importance of land and community in Aboriginal people's lives and connection to well-being
- provision for participation and representation of Aboriginal people at a decision-making level in health services
- increase Aboriginal health literacy with regard to cancer
- an atmosphere where Aboriginal patients can consult and use traditional healing approaches within mainstream medical care
- more Aboriginal health professionals providing support and care within the system.

Rather than blaming Aboriginal people for not accessing the cancer services, the focus of attention must be shifted to the whole system of treatment and health services. While patient-provider interaction and relationships are crucial for effective service delivery to Aboriginal people, health service providers also have a vital role in reforming the system, both inside and outside the hospital, so that institutional racism, the often alienating environment in which health care is delivered, and the lack of culturally appropriate support, information and understanding revealed in this study are addressed.

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## **APPENDICES**



# Aboriginal communities in Western Australia

Dept for Housing & Works Hierarchy March 2008

## Legend

### DHW Communities Hierarchy

- Hub communities
- Communities with populations over 100 people
- RAESP\* communities
- non RAESP\* communities

\*Remote Area Essential Services Program

### ICC Regions

- Kununurra
- Derby
- Broome
- South Hedland
- Kalgoorlie
- Geraldton
- Perth

□ LGA boundaries

— primary roads

— Aboriginal and Torres Strait Islander Representative Bodies (RATSIB)

— Yamatji Bana Baaba Marlpa Land and Sea Council incorporating Pilbara Native Title Service

— South West Aboriginal Land and Sea Council

— Kimberley Land Council

— Goldfields Land and Sea Council

— Territory of Ashmore and Cartier Islands

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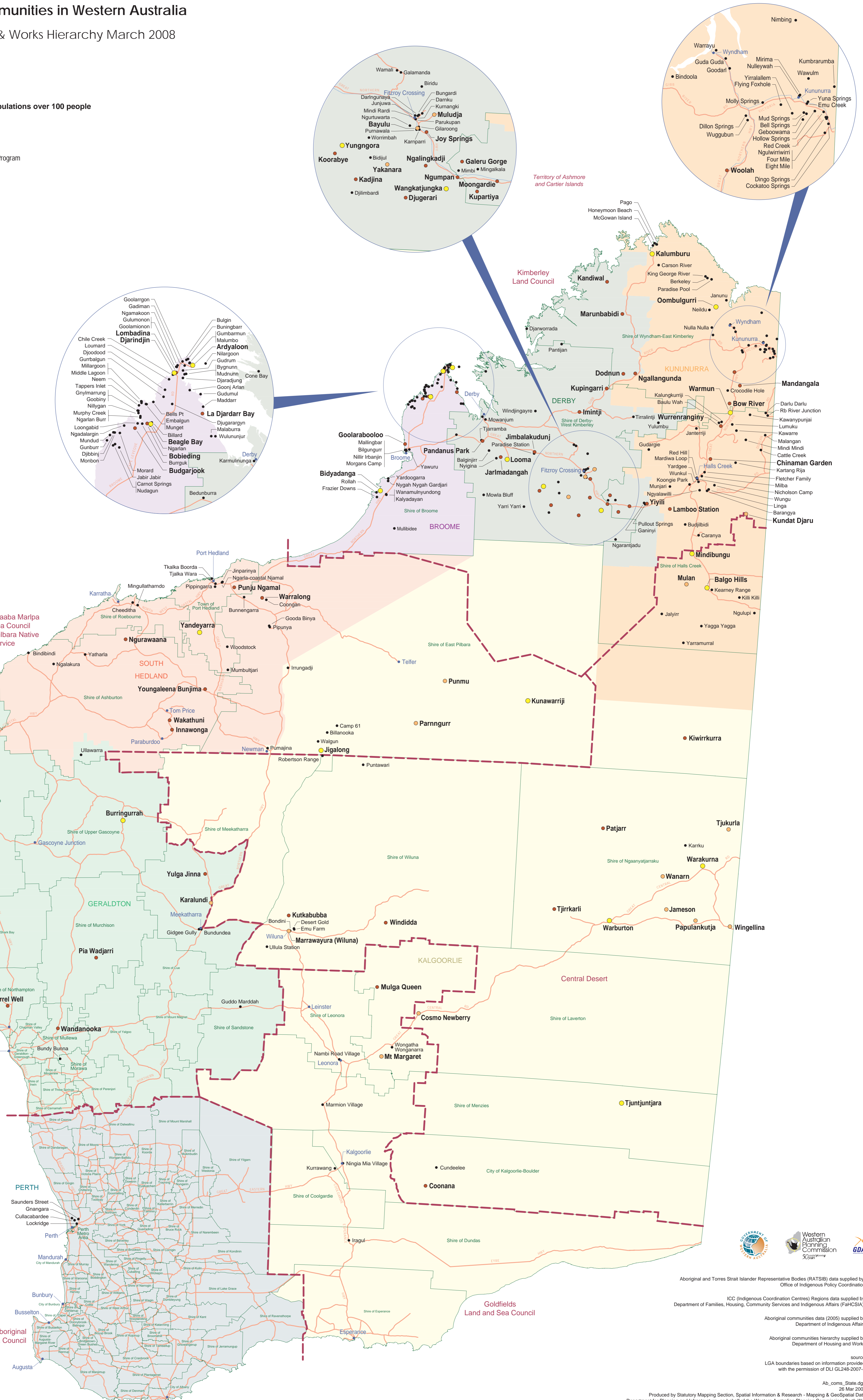
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Aboriginal and Torres Strait Islander Representative Bodies (RATSIB) data supplied by Office of Indigenous Policy Coordination  
ICC (Indigenous Coordination Centres) Regions data supplied by Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)  
Aboriginal communities data (2005) supplied by Department of Indigenous Affairs  
Aboriginal communities hierarchy supplied by Department of Housing and Works  
source: LGA boundaries based on information provided with the permission of DLI GL248-2007-2  
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Produced by Statutory Mapping Section, Spatial Information & Research - Mapping & GeoSpatial Data Department for Planning and Infrastructure, on behalf of the Western Australian Planning Commission, Perth WA



## **Information Sheet for Aboriginal Men and Women on Interviews for the Research Project on Rural-Urban Differences in Aboriginal Australian Perspectives on Cancer**

Cancer rates are increasing in Aboriginal Australians. Aboriginal people generally have their cancers diagnosed later than non-Aboriginal people, but even when diagnosed at the same stage, they tend to have a worse outcome. My research is designed to understand why this is, and what could be done to improve cancer services so that they respond better to the needs of Aboriginal people with the disease. My results will be made available to Aboriginal communities, health centres and those involved in health service planning.

My name is Shaouli Shahid. I am doing research at the Centre for International Health at Curtin University of Technology in Perth. I want to talk with you and hear your ideas about cancer, what you know about it and any good or bad experience you have had regarding this disease during screening, diagnosis, or treatment. I hope to use my findings to improve cancer related services for Aboriginal people.

Further information about taking part this project is provided below:

- I will be the person talking with you about cancer. I am interviewing Aboriginal men and women people who are aged at least 18 years.
- You are welcome to have a member from your family or community with you during the interview.
- I am interested in your views and experiences. There are no right or wrong answers.
- If needed, I can arrange culturally appropriate counselling for you to discuss anything that comes up or that causes you distress during the interview. Please let me know if I can assist you with this.
- With your permission, I would like to record your answers on audiotape so that your answers can be accurately understood and interpreted later on.
- Interviews may take 60 minutes. If you want to talk for longer, I am happy to spend extra time. It would be my pleasure.
- All information from the interviews will be kept confidential. Your answers will be kept very safe in a locker and the primary researchers will only be the people accessing that information.
- I will enter your answers into my computer but your name will not be inserted. No one will be able to match your name to the answers.
- The discussion will be conducted in English.
- I will pay you \$20 for any expenses you have associated with coming to the interview.
- If you are uncomfortable with any of the questions I ask, you do not have to answer it/ them. But, I hope you will answer them for the successful completion of the project.
- Your help with this project is completely voluntary. If you do not want to be interviewed then that's ok. It will not affect any of the services you receive.
- You can stop taking part in this project at any time you wish. You do not need to give any reason. If you withdraw, with your permission, I would like to include the answers you have already given.

- Reports and publications about the research will never use your name, and material will be presented in ways that will prevent anyone from being able to identify you.
- The project has been approved by the Curtin University Human Research Ethics Committee and Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC).
- If you would like to know more about this project, you can contact Shaouli or her supervisors. Their contact details are as follows:

<b>Shaouli Shahid</b> Centre for International Health Curtin University of Technology GPO Box U1987, Perth, WA, 6845 Phone: 08-9361-3994	<b>Sandra Thompson</b> Centre for International Health Curtin University of Technology GPO Box U1987, Perth, WA, 6845 Phone: 08-9266-3985	<b>John Mallard</b> Centre for Aboriginal Studies Curtin University of Technology GPO Box U1987, Perth, WA, 6845 Phone: 08-9266 3537
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Thank you so much for your time, help and kind cooperation.

## **Information Sheet for Health Service Providers on Interview for the Research Project on Rural-Urban Differences in Aboriginal Australian Perspectives on Cancer**

My name is Shaouli Shahid. I am doing research at Centre for International Health in Curtin University of Technology in Perth, Western Australia. My project is about to explore and understand Western Australian Aboriginal Australians' perspective (beliefs, understandings, perceptions), experiences and barriers in regard to cancer, cancer diagnosis, treatment in urban and rural settings. The incidence of cancer is increasing among Aboriginal Australians. The study findings can be utilized to improve cancer services for Aboriginal people, as the results will be distributed to relevant organizations. Just like this interview, I will ask about people's opinions and experiences in relation to cancer to several other individuals. You will be one of many health service providers who will be interviewed for this study. There are no right or wrong answers. I am interviewing people who are over 18 years old. These interviews will include both men and women. Other information about this project is given below:

- My name is Shaouli Shahid, and I will talk to you.
- Your answers will be kept very safe in a locker and the primary researchers will only be the persons accessing that information.
- I will enter your answers into my computer but your name will not be inserted. No one will be able to match your name to the response.
- Reports and publications about the research will never use your identity/ name, and material will be presented in ways that will prevent anyone from being able to identify you.
- The discussion will be conducted in English.
- Interviews may take up to one hour of your time. However, if you want to talk for longer, I am happy to spend extra time. It would be my pleasure.
- I wish to record your answers with your permission on audiotape so that your answers can be accurately understood and interpreted later on.
- You are not bound to answer all the questions, and you can withdraw from the study at any time.
- Your help with this project is completely voluntary. Refusal to participate will have no effect on your responsibilities as a service provider you are currently involved in any organisation.
- You will need to sign a consent form before taking part in the study. Your consent needs to be seen so that the researchers can be sure that you are not being pressured to be in the study.
- You can stop taking part in this project at any time you wish. You do not need to give any reason for that. If you withdraw, with your permission, I would like to include the answers you have already given.
- The project has been approved by the Curtin University Human Research Ethics Committee and Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC).

If you would like to know more about this research and want to take part in it and throughout the study, you will be able to contact one of the research team on the numbers given below. They will be happy to answer any questions you have about the study.

<b>Shaouli Shahid</b> Centre for International Health Curtin University of Technology GPO Box U1987, Perth, WA, 6845 Phone: 04-3381-8850 (Mobile) 08-9266-3226 (Work)	<b>Sandra Thompson</b> Centre for International Health Curtin University of Technology GPO Box U1987, Perth, WA, 6845 Phone: 08-9266-3985	<b>John Mallard</b> Centre for Aboriginal Studies Curtin University of Technology GPO Box U1987, Perth, WA, 6845 Phone: 08-9266 3537
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Thank you so much for your time, help and kind cooperation.



## Consent Form

I agree to participate in the study Rural-Urban Differences in Aboriginal Australian Perspectives on Cancer.

The purpose of the study has been explained to me.

I am free to ask questions.

I have freedom to ask for any help.

I understand that I can withdraw from the study at any time.

I understand that any information about the research will not use my real name or information that can identify me.

I am/ am not giving my permission to having my interview recorded.  
*(please circle)*

Signed (participant) \_\_\_\_\_

Date \_\_\_\_\_

Signed (researcher) \_\_\_\_\_

Date \_\_\_\_\_

## Consent Form

I agree to participate in the study Rural-Urban Differences in Aboriginal Australian Perspectives on Cancer.

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I am/ am not giving my permission to having my yarning recorded.  
*(please circle)*

Signed (participant) \_\_\_\_\_

Date \_\_\_\_\_

Signed (researcher) \_\_\_\_\_

Date \_\_\_\_\_

## **Interview Questions for who have directly suffered from the disease**

Note for the Readers

These are tentative enquiries only. The interview will be more of a conversation than an interview *per se*. I want to listen to, and record, participants' experiences. No questionnaire will be administered. Listed below are the topics that I would like to cover during the course of my conversations with cancer patients.

### **1. Diagnosis**

(a) I'd like to ask you about your experiences with regard to your illness.

Would you please tell me:

- How you came to know that you were not well?
- What sort of symptoms did you have?
- Do you know what type of illness you have?
- In the beginning, when you suspected something was not right or you did not feel well, where did you go/who did you ask for help?
- Did you face any sort of problems when you went to find out what was wrong? If you did, could you please tell me about the problems?

(b) If he/she is lately diagnosed, what could be the reason in his/her opinion?

### **2. Perception and Knowledge**

Now I would like to talk with you about what you knew about the illness before and possibly about some of your feelings? If there is anything that you don't want to talk about we will just go on to the next bit so just let me know.

#### **(a) *On perception***

- Do you think you could tell me about your feelings when you were first told that you were not well? What sort of worries did you have?
- Who was the first person you told about your illness?
- How long after did you tell ...? (Say the name of the person told)
- How did he/she react? Do you think they were sad/ angry/ frightened/ upset/ sympathetic?
- How did their reaction affect you?
- Do you ever discuss your illness with anyone from your family or your community? If you do, what sort of things do you talk about? If you don't discuss your illness, are there reasons why you don't talk with people about it?

#### **(b) *On knowledge and beliefs***

- Did you know anything about the illness before you got it yourself? What sort of understanding did you have about the illness, for example, about different types of cancer, causes, possible consequences, treatment, etc.?
- For you, what sort of cultural or spiritual beliefs, understandings or meanings were associated with cancer before you were told that you had the illness?
- What do the cultural and spiritual matters around this disease mean to you and to your family/community?

- Have any of these meanings changed for you now since you found out that you have cancer?
- How do you cope with your life now after being told that you have this illness (with your family, your community, your work)?
- How do you feel when you think of this? What sort of changes (physical, mental, social, economical, cultural) did you feel after being told you have this illness?

### **3. Treatment**

- Could you please tell me what did you do after you were told that you have this illness? Did you go for treatment straight away? If yes, where did you go (traditional healer or western doctor)? If you didn't go to a healer or a doctor, what specifically did you do?
- What did the doctor/ traditional healer who you went to see first, say to you about your illness, possible treatments, dangers, outcomes, side-effects? Do you think you were well-informed and well-understood by whoever it was that you went to see?
- I would like to know about your experiences (both positive and negative) with your first treatment and also with later treatments for your illness. How did you find it? Was it difficult? If „Yes’, what sort of problems/ difficulties did you face during treatment (eg, getting to the place, the treatment itself, the medicine, having to come for check-ups, cultural, social, financial, and any others)?
- Did you get support from your family, community and other individuals during treatment? What sort of support did you get? Are you still getting the same support?
- Are you satisfied with the types of support you have received from the place you go for treatment? In what way do you think it meets/ does not meet your needs?
- Do you have to go for treatment for your illness on a regular basis? Do you always go when you have an appointment to go? Do you find any difficulties in doing that? If „Yes’, could please tell me what sort of difficulties you have?
- Does your treatment cost you a lot of money? What sorts of costs are there for you (eg, travel, medicine, accommodation, food, etc)? How do you manage to pay these costs?
- Have you ever been to any traditional healers? If „Yes’, could you please tell me about how he or she helped you to overcome your pain/ grief? Why did you go to them?

### **4. On Improvement of Services**

- What do you think Aboriginal people should do after being diagnosed with the illness? What lessons have you learned from your experiences that could be shared with others?
- In your opinion, what sort of services specific to the illness you have should there be for Aboriginal people? Should the services for Aboriginal people be the same as for other Australians?
- What would you suggest to improve the services for Aboriginal people, and how can they be made more culturally sensitive?
- What do you think are the existing barriers for Aboriginal people with respect to these services, including screening, diagnosis and treatment? Please explain by highlighting your own personal experiences.

## **Interview questions for people *who have* close but indirect experience with cancer**

**The potential questions are for people who have close but indirect experience with cancer (that is, having cancer in their family or within the community to which he/she is closely attached.)**

Note for the Readers

Please note that these are only tentative enquiries. It is intended that the interview will again be more of a conversation than an „interview’. I want to listen to, and record, participants’ experiences. No questionnaire will be given to them. Listed below are the topics that I would like to cover during the course of my conversation.

During our time here together I would like to ask you about your knowledge, your beliefs, attitudes and understanding of the disease “cancer”. First I would like to ask who it is that you know who has cancer?

### **1. Perception and Knowledge**

- Could you please tell me what you know about cancer? How do you feel when you hear that someone who you know has cancer?
- How did you come to know about cancer? From whom, or from where?
- Is there any sort of specific cultural, spiritual meanings or beliefs attached to cancer for Aboriginal people?
- How did you feel when you heard that \_\_\_\_\_ has “cancer”?
- What sort of concerns came to your mind?
- What type of understanding did you have about cancer before your \_\_\_\_\_ was told about their cancer? For example:
  - about different types of cancer
  - possible causes
  - possible consequences
  - available treatment, etc.,
  - do you think that understanding has changed now since .....was told about their cancer?
- When \_\_\_\_\_ told about his/her cancer, what was the reaction of:
  - Your family?
  - Your community?
  - What was your role?
- What sort of support were you able to give to.....? (Use the name of the person with cancer)
  - What do you think are the issues/ perceptions around this disease for you, your family and the Aboriginal community?
  - Do you find people discussing this disease pretty easily in your family/community or is it something that people don’t talk about?
  - Sometimes Aboriginal people do not find out that they have cancer until they have had it for a long time. I would like to ask if you could please tell me about any of the beliefs that Aboriginal people might have with regard to “cancer” that may contribute to their late diagnosis.
  - Can you think of any other possible reasons that can cause this late diagnosis of cancer among Aboriginal people?

## **2. Prevention, Diagnosis and Treatment**

- Could you please tell me what you know about cancer prevention? How have you heard about this?
- Could you please tell a little bit about how you think Aboriginal people find out that they have cancer? Can you remember where your \_\_\_\_\_ went and then found out that he/she had cancer?
- Do you know anything about what type of problems he/she had before he/she was told they had cancer? How would they describe the problems?
- Could you please tell me about what happened after ..... was told that he/she had cancer? Did ..... go for treatment straightway? If he/she did go for treatment straight away, where did ..... go? If .....didn't go for treatment straight away would you be able to tell me what did they do?
- Have you heard Aboriginal people discussing the kind of experiences (either positive or negative) they have had with initial and later treatment for cancer.
- What sort of significant problems might they have had during treatment (including access, treatment, medicine, follow-up, cultural, social, financial, and many more)?
- From your experience, what do you know about traditional healers helping cancer patients with his/her pain, grief, discomfort, treatment or anything else?
- Do you know anyone going to traditional healers? If it is related to any kind of diseases, why do you think they go to traditional healers instead of going to a western medical doctor?

## **3. On Improvement of Services**

- Can you please tell me what you know about cancer prevention services for Aboriginal people?
- Please describe what you know of existing services for Aboriginal people with cancer.
- What do you think Aboriginal people should do after being told that they have cancer? Have you learned anything from your own experiences that you could share with other Aboriginal people?
- How do you think the cancer services for Aboriginal people should be organized?
- What would you like to suggest for improving cancer-related services and outcomes for Aboriginal people?
- How do you think cancer services could be made more culturally-sensitive? Think of your own experiences with your \_\_\_\_\_.
- What do you think are the existing barriers for Aboriginal people with respect to cancer services, including prevention, screening, diagnosis and treatment? Please explain by relating to your own personal experiences.

# **Interview and focus group questions for people who *do not have* any personal experience with cancer**

## **Note for the Readers**

These are only tentative enquiries. It is intended that the interview will be more of a conversation than an „interview’. I want to listen to, and record, participants’ experiences. No questionnaire will be given to them. Listed below are the topics that I would like to cover during the course of my conversation.

### ***1. Perception and Knowledge***

- I would like to ask you to tell me what you know, or what you have heard, about cancer?
- How did you come to know/hear about it? From whom, or from where?
- Can you tell me how you feel when you hear that someone has cancer? Could you briefly tell me about the thoughts that might come to your mind?
- Are there any cultural or spiritual meanings/ beliefs/ understanding that are attached to cancer among Aboriginal people?
- Would you be able to tell me about any beliefs that Aboriginal people might have with regard to “cancer” that might explain why fewer Aboriginal people go for screening and many do not get diagnosed until they have had cancer for a long time.
- What type of understanding do you personally have about cancer, for example, about different types of cancer, about possible causes and consequences, treatments, etc.?
- What do you think are the perceptions/ issues for Aboriginal people with cancer? Do people easily discuss this disease in your family or your community?

### ***2. Prevention, Diagnosis and Treatment***

- Could you please tell me what you personally know about cancer prevention? How have you heard about this?
- Could you please tell a little bit about what you know of how people find out that they have cancer?
- Do you know anything about the kinds of things that people might feel is wrong that might make them go to find out what’s causing this?
- Have you heard Aboriginal people discussing the kind of experiences (either positive or negative) that they have had with their first and later treatments for cancer. What sort of significant problems have they had during treatment (including access [ie, distances that have to be traveled, limited times available, etc], treatment, medicine, follow-up, cultural, social, financial, any others)?
- What do you know about traditional healers helping cancer patients with his/her pain, grief, discomfort, treatment or anything else?
- Do you know of anyone who is going to a traditional healer? If it is related to any kind of physical sickness, why do you think they go to a traditional healer instead of going to a western medical doctor? Do you think that Aboriginal people have more trust in a traditional healer than in western medicine?

### ***3. On Improvement of Services***

I would like you to please tell me what you know about cancer prevention services for Aboriginal people.

- Would you please tell me what you know of existing services for Aboriginal people with cancer?
- How do you think the cancer services for Aboriginal people should be organized? What would you like to suggest for improving cancer-related services for Aboriginal people so that they are more culturally sensitive and appropriate and might be better used by Aboriginal people?
- What do you think are the existing barriers for Aboriginal people with respect to cancer services, including prevention, screening, diagnosis and treatment? Please explain by highlighting any personal experiences that you may have had.



## **Interview and focus group questions for Health Service Providers**

### ***Note for the Readers***

These are only tentative enquiries. It is intended that the interview will be more of a conversation than an „interview’. I want to hear and appreciate the experience of participants. No questionnaire will be given to them. Listed below are the topics that I would like to cover during the course of my conversation.

1. Who are the Aboriginal groups with whom you work?
  - Cancer patients
  - Aged care
  - Adolescents
  - Others (please specify)
2. What available documentation do you have about your clients/patients? (e.g., are they coming from rural or urban areas, their level of education, do they have English as a 1<sup>st</sup> language, their date of diagnosis, stage of the disease, etc.)
3. How do the cancer patients get referred to you? How do you get them here (e.g., is transport provided??)
4. Please describe in detail what sort of services you provide for Aboriginal patients with cancer.
  - Please specify the services differentiated by sex
5. How would you describe an Aboriginal cancer patient if you think in terms of diagnosis, treatment and follow-up as compared with a non-Aboriginal patient?
6. I'd like to ask you about issues that you face while providing services for Aboriginal men and women. Please think about the Aboriginal cancer patients you have helped and can you please try to identify the types of experiences/ problems/ issues you have had to cope with? For example, are these patients reluctant to come for follow-up treatment/examinations, their preferences in terms of food, accommodation, traveling etc?
7. What do you know of the beliefs and understandings that Aboriginal people have with regard to cancer? Please tell me about them.
8. What do you think are the reason why many Aboriginal people are diagnosed at an advanced stage of their cancer and why do they have a lack of continuity of treatment?
9. What do you think are the existing barriers for Aboriginal people with respect to cancer services, including prevention, screening, diagnosis and treatment? Please explain by highlights from your own experiences.
10. What do you think are the most culturally appropriate ways to address the issues we have been discussing?
11. In your opinion, how should the cancer services for Aboriginal people be arranged/ organized? What would you like to suggest for improving cancer-related services for Aboriginal people?

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Yours sincerely

Shaouli Shahid

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Yours sincerely

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14 December 2009

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