Exposed



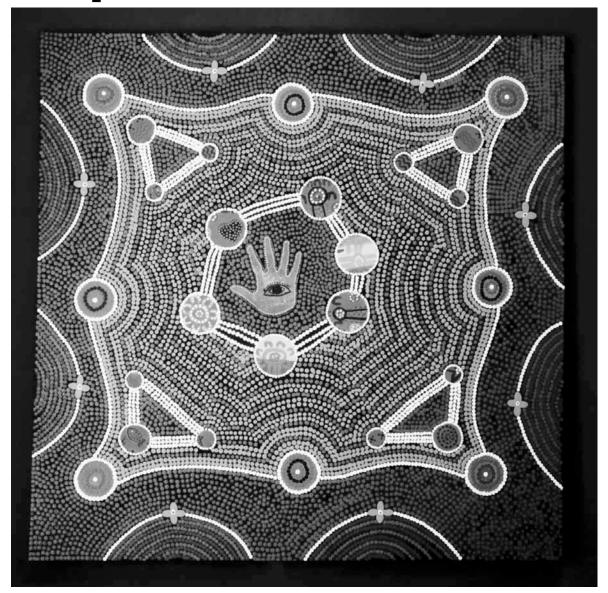
A literature review of the issues of women's cancers in Australian Indigenous Communities

"In the past we were happy and free from sickness, and in the future we will become strong and healthy again." (Anangu Pitjantjatjara people of Central Australia)



Challenging inequity, embracing diversity.

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Women's Health Goulburn North East (WHGNE) was established in July 2000. Previously known as NEWomen, WHGNE is the government funded specialist women's health service for the Goulburn Valley and North-East Victoria. The vision is to lead the Hume region in creating opportunities for women to experience a positive sense of self, health, safety and wellbeing.

Contact WHGNE

PO Box 853, Wangaratta, Victoria, 3677

Phone: 03 5722 3009 Fax: 03 5722 3020

Email: whealth@whealth.com.au Webpage: www.whealth.com.au

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Executive Summary

Australia is one of the healthiest countries in the world, and yet Aboriginal and Torres Strait Islander¹ people still have life expectancy and rates of illness akin to developing countries. The burden of disease suffered by Aboriginal Australians is estimated to be two-and-a-half times greater than the burden of disease in the total Australian population. Given the medical and social issues often faced by Aboriginal women, cancer must be considered in the light of these other priorities.

Cancer shows no discrimination against race, gender, social position or wealth. The past two decades have seen a 30% reduction in cancer mortality rates in Australia, yet these successes have not been shared by Aboriginal people. Deaths from cancer in Aboriginal Australians are generally much higher than expected, at nearly two to four times the rate of other Australians with cancer. Aboriginal survival is lower than that for non-Aboriginal people for almost all cancer sites.

Exposed: a literature review of the issues of women's cancers in Australian Aboriginal communities explores how Aboriginal women experience cancer, with a lens on the rural Hume region of Victoria. The Hume Regional Integrated Cancer Service reports the largest percentage of the total new cancers diagnosed in Aboriginal people in the state of Victoria, which is even higher when Albury NSW cases are included.

¹ Throughout this report, we will refer to 'Aboriginal and Torres Strait Islander' people as 'Aboriginal' people. The Victorian Department of Human Services 2006 publication, *Building Better Partnerships* states the definition of 'an Aboriginal or Torres Strait Islander is: a person of Aboriginal or Torres Strait Islander; who identifies as an Aboriginal or Torres Strait Islander; and is accepted as such by the community in which he or she lives. (Burney 1994, cited in Victorian State Government Department of Human Services, 2006).



The Australian Aboriginal population suffers disproportionately from cancer in several ways. Firstly, compared with the general population, Aboriginal Australians have a higher incidence of cancers with poor outcomes and a lower incidence of cancers which generally respond well to treatment. Even when afflicted with the same cancers, the outlook for Aboriginal people is worse.

The limitations of the available incidence and mortality data² should be recognised at the outset. The data is clearly incomplete. As the accuracy of Aboriginal identification by service providers and States varies, the data presented throughout this report should be taken as indicative rather than absolute. So while the data does not present a complete picture, there is a consistent pattern of large differences between Aboriginal and non-Aboriginal Australians in (1) incidence of cancer at several specific sites, (2) cancer death at most sites and (3) cancer survival.

Despite general improvements in participation levels in the national cancer screening programs for the early detection of breast and cervical cancers, Aboriginal women remain underrepresented and are less likely to have cancer found at an early stage, when treatment can be most successful and more options are available.

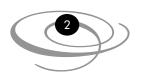
The reasons underlying the inequity in cancer outcomes between Aboriginal and non-Aboriginal Australians are multi-factorial and not yet fully explained. Advanced cancer at diagnosis, reduced completion of cancer treatment, higher rates of co-morbidities and lifestyle factors are some of the issues leading to the poorer cancer outcomes recorded. Aboriginal Australians, like Indigenous populations in comparable countries, are over-represented in low socio-economic strata which is associated with poorer health and increased exposure to health risk factors.

Aboriginal women diagnosed with cancer may find it difficult to obtain adequate information about treatment options and may have difficulty understanding the medical terms or 'jargon' used. There is a perception that treatment is not culturally appropriate, and there may be practical difficulties in travelling for treatment.

The direct relationship between Aboriginal cancer mortality and remoteness of residence remains unclear and disentangling the effects of geographical isolation and a relative shortage of health care providers from other factors, such as disadvantage, cultural differences and data quality, is difficult, although all are acknowledged as contributing factors to diagnoses at a later stage.

There is a prevailing belief among Aboriginal women that cancer is a 'deadly disease' and that treatment is mostly futile. This view is understandable since many Aboriginal people witness the suffering and rapid death of family and friends who have advanced cancer when diagnosed. In addition to fearing the disease itself, the women fear being controlled by the white man's hospital system and vulnerable to that authority. The maze that confuses so many cancer patients is completely unnavigable for many Aboriginal people, given the financial, organisational, geographic and communication barriers. Many simply withdraw from active treatment after their initial experience of it.

² Data is sometimes treated as a mass noun and used in the singular. This usage is inconsistent with the rules of Latin grammar and traditional English, which would instead suggest plural. Usage now widely accepts treating data as singular in standard English, therefore for ease of reading this literature review, data is referred to as singular. (http://en.wikipedia.org/wiki/Data Accessed 22/3/09 @ 10:52 am).



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The little data comparing Aboriginal and non-Aboriginal women suggests that at the population level, Aboriginal women may be at less risk of breast cancer. The lower incidence of breast cancer can be partially explained by the differences in age structures of the populations and undercount, and protective factors including early pregnancies, multiple pregnancies and possibly longer duration of breast feeding. However, despite the lower incidence of breast cancer, it is the second leading cause of cancer deaths in Aboriginal women (after lung cancer) with mortality from breast cancer 9% higher than for the Australian female population.

Aboriginal women face a significant survival disadvantage compared with other Australian women from cervical cancer - a potentially curable cancer. Reductions in cervical cancer mortality have occurred for Aboriginal women, but both incidence and mortality rates remain considerably higher than national rates. Compared with Aboriginal women living in metropolitan areas, Aboriginal women living in a rural or remote area have approximately twice the likelihood of dying from cancer of the cervix. This is likely to reflect the relatively poor access to and utilisation of screening services for Aboriginal women in rural and remote areas and raises questions about access to services for prevention and early diagnosis and the suitability of services offered.

The health sector must ensure that the high level of cancer prevention, detection, and management that is available is as accessible to, and appropriate for, Aboriginal people as it is for other Australians. While the health system cannot deal directly with all of the socio-economic, cultural and historical factors, it can rise to the challenges of preventing the occurrence and progression of disease and reduce suffering for Aboriginal Australians as effectively as it does for non-Aboriginal Australians. Cancer should not be considered apart from other health problems; many of the improvements required in disease-prevention programs and diagnosis and treatment services to reduce cancer incidence and mortality are the same improvements needed to reduce the impact of other health and social problems.

Culturally safe healthcare advocates for a bicultural model that promotes the distinction between cultures rather than merely acknowledging cultures other than the dominant society. A bicultural approach requires adjustment in the entire healthcare system. To improve Aboriginal women's access to appropriate and timely treatment, health care professionals should advocate for a culturally safe and culture-centred approach, upholding the values and beliefs that are culturally significant in decision-making about a sick person's treatment and care.



Introduction

Women's Health Goulburn North East (WHGNE) is the government funded specialist women's health service for the Goulburn Valley and North-East of Victoria (Hume region). Since 2006 Women's Health Goulburn North East, in partnership with BreastScreen Victoria (BSV) and many regional health services, has conducted *The BreastScreen Van Women's Cancers Project*, a multifaceted and holistic approach to breast health in the Hume region of Victoria. This initiative emerged from recommendations in the Woman to Woman breast cancer research and companion book of women's stories, which were published by WHGNE in 2004.¹

Cancer diagnosis has a massive impact on individuals, their families, the community, and the health system. The estimated annual health expenditure due to cancer in 2000-2001 in Australia was \$2.7 billion² and was the main underlying cause of death from 2002-2004, causing 28% of all deaths each year.³ For women, the number of new cases of cancer diagnosed is predicted to rise by 29% from 40,578 in 2001 to 52,356 in 2011.⁴

The outlook for Aboriginal people is worse, as this population suffers disproportionately from cancer. Early detection is less likely for Aboriginal than non-Aboriginal women, and Aboriginal women are less likely to have access to and/or receive or complete treatment. There are likely to be co-morbidities and diagnoses are often of advanced disease. Exposed: a literature review of the issues of women's cancers in Australian Aboriginal communities explores how Aboriginal women experience cancer, with a lens on the rural Hume region of Victoria.

Hume region of Victoria

The Hume Region extends over 40,000 square kilometres of North East Victoria and the Goulburn Valley, about a fifth of the state of Victoria. The Region contains twelve local government areas, four provincial centres and many clusters of small, remote populations. It is geographically diverse as it includes Victoria's Alpine areas, some relatively remote farming communities and the major regional centres of Wangaratta, Shepparton and Wodonga.⁵



Several towns, for example, Wodonga and Cobram, border New South Wales (NSW) towns. This division across the Murray River has implications for data collection and health services, some of which are noted in this report. The vast majority of literature and data on cancer in the Aboriginal population comes from states other than Victoria, where little is found. Statistics and data from Victoria and southern NSW have been included when available.



Table 1 provides data on the estimated Aboriginal female population for Victoria in 2006,⁶ although it is generally acknowledged that this is an undercount of actual numbers.⁷

Table 1: Estimated Aboriginal female population Victoria 2006

Estimated Aboriginal female population Victoria				
Year	Hume region	Regional Victoria	Victoria	
2006	1928	8227	15397	

The Australian Bureau of Statistics (ABS) suggests 1928 of the Hume region population are Aboriginal women, with most living in the areas of City of Greater Shepparton, Albury-Wodonga and the Mitchell and Moira Shires. This is 1% of the population compared to 0.6% for Victoria. Local estimates, however, place the Aboriginal population of City of Greater Shepparton alone at between 4,000 and 6,000.8

Methodology

The search strategy used to locate research on women's cancers in Aboriginal communities involved analysing academic, peer reviewed journals using the literature databases of Informit, CINAHL, Ovid MEDLINE, the Women's Health Victoria Clearinghouse catalogue and relevant books. The original selection criteria to locate articles and books for inclusion in this literature review were publications which contained the keywords "Indigenous and/or Aboriginal, health, cancer, oncology, neoplasms, cancer care facilities". Data was obtained from state based cancer councils and services, such as Cancer Council and BreastScreen Victoria, and national government websites including Australian Institute of Health and Welfare and Australian Bureau of Statistics. The focus was on Australian rural research, with very little found from Victoria or within the Hume region. Some international articles were sourced. From these, we continued to identify further articles using the references sections of the previously retrieved articles. We focused on articles from the last decade, using the most current data.

Aboriginal population demographics

Assessment of a population's health status, which is, in fact, assessment of its ill-health (that is, death and disease), requires accurate information about the numbers of specific health conditions, occurrences and the size of the population. There have been improvements in the data informing Aboriginal health status in recent years, but the quality and completeness of the data is often unknown and may vary between jurisdictions and between different data sources. 9,10,11,12 Many of the rates of illness reported are likely to be underestimates in the Aboriginal population because of the under-identification of Aboriginal people in these data collections. Each Census in Australia, a greater number of people are missed than are counted more than once and the overall effect is called net undercount. Compared with the general population, which is estimated to be about 3%, some data suggests under-counting is 15-30% in the Aboriginal population. 13

Two characteristics mark the Aboriginal population. It is relatively young compared to the non-Aboriginal population and it is a growing population. Table 2 shows the differences in the age structure. ¹⁴ In the Hume region, 57% of the Aboriginal population is under the age of 25, compared to 39% for the general population. ¹⁵ The ABS proposes this is largely the product of higher rates of fertility and the shorter life expectancy among the Aboriginal population.

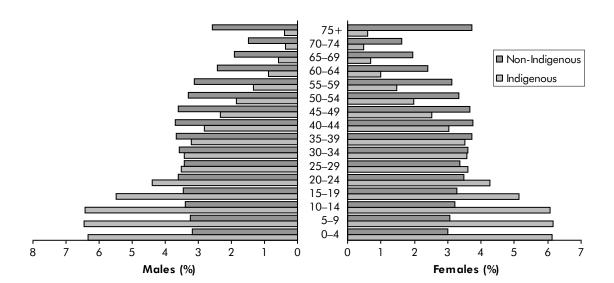


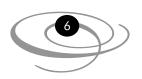
Table 2: Age and sex distribution of Indigenous and non-Indigenous populations, 2006

Health status of Aboriginal Australians

The health status of Aboriginal Australians is alarming and comparable to figures in the third world. Whilst the World Health Organisation (WHO)¹⁶ confirmed that the general population of Australia is one of the healthiest of any developed country, the Australian Aboriginal population is one of the least healthy of all Aboriginal populations within comparable developed countries,¹⁷ and does not have the same level of access to appropriate health care as the general population.¹⁸ For instance, life expectancy at birth for the period 1996-2001 was 65 years for Aboriginal women; in contrast, for non-Aboriginal women it was 17 years longer.¹⁹ The data on Aboriginal infant mortality, which is three times the rate of non-Aboriginal Australians, further illustrates this startling disparity.²⁰

The burden of disease suffered by Aboriginal Australians is estimated to be two-and-a-half times greater than the burden of disease in the total Australian population. About one-third of Aboriginal patients have another condition such as diabetes and are 1.7 times more likely to have three other medical conditions or more.²¹

The causes of Aboriginal ill-health are complex and multi-faceted. The major factors attributing to the poor health status of Aboriginal Australians and in particular Aboriginal women, who suffer extremely high levels of disadvantage, include socioeconomic status (including education, income, and employment); social and cultural factors (including dispossession, dislocation, racism, high levels of violence and the breakdown of community structures based on respect and authority); access to good quality health care; physical environmental factors; and specific health risk factors.^{22,23}



There is strong evidence that low socioeconomic status is associated with poor health and increased exposure to health risk factors. ^{24,25} In 2006, the median weekly gross household income for Aboriginal people (\$362) was equivalent to only 56% of the corresponding income for non-Aboriginal people (\$642), and the unemployment rate was higher for Aboriginal people than non-Aboriginal people (16% compared with 5%). ²⁶ The socioeconomic disadvantage experienced by Aboriginal people places them at greater risk of exposure to behavioural and environmental risk factors, ²⁷ including smoking, alcohol consumption, obesity and inadequate fruit and vegetable intake. ²⁸ Aboriginal Australians are also far less likely than non-Aboriginal Australians to have educational qualifications and research has shown that this causes further disadvantage, given that higher levels of educational attainment are associated with better self-assessed health and physical functioning, and lower levels of morbidity and mortality. ^{29,30}

The health impact of rurality

More than a third of Australians live outside major cities³¹ where there are implications for access to preventative, diagnostic, curative, and palliative services, as well as to basic health infrastructure and economic opportunities. For some cancers, remote patients were up to three times more likely to die within five years of diagnosis. The higher proportion of disadvantage is acknowledged to be a contributing factor.³²

In 2006, an estimated 32% of the Australian Aboriginal population were living in major cities, 43% in regional areas and one-quarter in remote areas.³³ In Victoria, almost half the Aboriginal population is located in rural areas.³⁴ Aboriginal people are more likely to die from cancer the further they are located from major cities.^{35,36,37} The direct relationship between Aboriginal cancer mortality and remoteness of residence remains unclear and disentangling the effects of geographical isolation and a relative shortage of health care providers from other factors, such as disadvantage, cultural differences and data quality, is difficult.³⁸ However, all are acknowledged as contributing factors to diagnoses at a later stage.³⁹

Aboriginal views and definition of health

Aboriginal concepts of health usually embrace a complex web of relationships involving the land and the social, physical, emotional and spiritual being of people and their communities. In contemporary society, many Aboriginal people view their culture as of paramount importance to their health and to the wellbeing of the community. The National Aboriginal and Islander Health Organisation states that health is:

'…not just the physical well being of the individual, but the social, emotional and cultural well being of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life.' ⁴⁰

The Aboriginal concept of "life is health is life" is defined to include body, spirit and land.⁴¹ This extends not only to health at an individual level but the health of family and the health of community. Women see their health as an integral part of the health of others, and accordingly a lack of a sense of community is often associated with ill health.⁴² Individual wellbeing is linked to obligations to society and the land itself,⁴³ a living interrelationship of culture and health in which any disturbance of one has a negative impact on the other.⁴⁴ Holistic health care in this sense refers to whole communities rather than simply whole bodies.⁴⁵



Research found that many Aboriginal women associated illness with a spiritual belief system. For example, some remote women related cancer to the 'payback system', whereby pathology was associated with factions in social and tribal relationships, 46 while other Aboriginal women did associate breast cancer with lifestyle factors, such as smoking, alcohol, diet, exercise and stress.

Relationship between health and healing

In recent decades there has been a marked shift towards a more holistic approach to health care which considers gender, age, ethnicity, religion and socio-economic class. However, Aboriginal communities have not benefited greatly from this approach.⁴⁷ It is proposed that this is due largely to three factors: ⁴⁸

- A generally poor understanding of the way Aboriginal people think about the nature of reality and, more particularly, about human life, knowledge and value
- An inability to notice the extent to which this thinking shapes the practical, daily lives
 of Aboriginal people
- A reluctance to recognise that these beliefs and practices differ from those of mainstream European Australians in significant ways.

For Aboriginal people, personal identity is holistically defined in terms of kinship, ritual, and spiritual relationships and responsibilities, all of which are inseparable from each other and the land, and nature.⁴⁹ Although most have been influenced in varying degrees by the European way of life, there are few who do not remain profoundly motivated by the fundamental assumptions of their Aboriginal philosophical heritage.⁵⁰

Many Aboriginal women have their own healing systems. Women may adhere to traditional medicines, and spiritual healers connect women with 'mother earth' beliefs, often concurrently with Christian beliefs. Both may run parallel to or complement accepted western therapies. Although health practitioners may not recognise the value of Aboriginal healing systems or alternative therapies, Aboriginal women continue to use them, sometimes without consulting or advising medical practitioners, often to avoid denigration of the practice. ⁵¹

Aboriginal women's perceptions of cancer

A study of rural Aboriginal women's perception of cancer found that women were generally well-informed about physical causes of cancer but apportioned some blame for the disease to the effects of 'white man's' colonisation which denigrated cultural values and the traditional way of life. In this study, one community elder explained

'Cancer wasn't heard of in the old days... they would get their own food, the food was good and [the people] never really got sick. Cancer is a disease brought by the white man. It must be if there was no cancer before that'. ⁵²

Some Aboriginal women associated cervical cancer with factors related to disadvantage, and blamed cancer on the loss of a traditional lifestyle after colonisation.⁵³ There is a prevailing belief among Aboriginal women that cancer is a 'deadly disease' and that treatment is mostly futile.⁵⁴ Most Aboriginal women know someone who has been diagnosed with cancer, and most have died from the disease.^{55,56,57}



A diagnosis of cancer appears to inspire some women to prioritise their cultural needs. Among the Yolgnu people for example, each part of the body represents a spiritual link to individual members of the extended family; to have a cancer in a certain organ may be the result of offending the relative whom that part of the body represents, a belief, which underscores a deep regard for kin. A person who believes his or her cancer is "payback" for offending a family member may not pursue treatment.^{58,59}

Indeed, many women choose to forego conventional cancer treatment and instead return to the security of being with their family and social networks and in their 'own country'.⁶⁰ Such situations may thus give rise to ethical dilemmas as to whether the treating doctor should proceed with treatment and subsequently breach culturally and historically derived laws, or withhold treatment altogether.⁶¹ It is important that cultural practices are accommodated when the patient is near the end of life because the place and manner of death have cultural and spiritual significance.⁶²

The concept of cultural safety

Differing perceptions of health and healthcare practices are fundamental causes of misunderstanding between cultures. When the different world views are not understood or respected, tension arises in the relationship with the minority culture³ feeling disempowered and vulnerable.⁶³

The concept of cultural safety was pioneered in New Zealand by Dr Irihapeti Merenia Ramsden. It means:

An environment which is spiritually, socially and emotionally safe, as well as physically safe for people, where there is no assault, challenge or denial of their identity of who they are or what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning together with dignity and true listening.⁶⁴

A lack of cultural safety is a major factor in Aboriginal people's mistrust of research and health service delivery. 'Unsafe cultural practice is any action that diminishes, demeans or disempowers the cultural identity and well-being of an individual or group'.⁶⁵

Culturally safe healthcare advocates for a bicultural model that promotes the distinction between cultures rather than merely acknowledging cultures other than the dominant society. A bicultural approach requires adjustment in the entire healthcare system.

Cultural safety is about power relationships in ... service delivery. It is about setting up systems which enable the less powerful to genuinely monitor the attitude and service of the powerful, to comment with safety and ultimately to create useful and positive changes which can only be of benefit to (healthcare) and to people we serve.⁶⁶

³ The United Nations describe minority groups as 'those non-dominant groups in a population which possess and wish to preserve ethnic, religious or linguistic traditions or characteristics different from those of the rest of the population'. In Prior, Palliative Care... p 109.



Dr Deb Prior's studies suggest that to improve Aboriginal women's access to appropriate and timely treatment, health care professionals should advocate for a culturally safe and culture-centred approach, upholding the values and beliefs that are culturally significant in decision-making about a sick person's treatment and care. For example, an important cultural value for Aboriginal communities is the role of the family in the support and care of the sick person as well as ensuring they have access to traditional healers and medicines. To promote culture-centred cancer care, health professionals should have some knowledge of Aboriginal culture and understand the impact of history on the people's attitudes toward conventional health care. A cultural safety centred approach requires health professionals to respect the different world views about a disease like cancer and to recognise these differences as strengths, not barriers, and that the cultural strengths are the bases for appropriate cancer care.⁶⁷

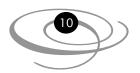
Customs about birth, death and other important life markers differ between Aboriginal and non-Aboriginal cultures and models of service delivery based on an Anglo-celtic world view are often alien to Aboriginal communities. ^{68,69} Westernised health care systems are slow to learn from Aboriginal peoples in Australia and other places, that maintenance of wellness, not management of illness, should be the goal. ⁷⁰

Barriers to seeking and receiving care

The reasons underlying the inequity in cancer outcomes between Aboriginal and non-Aboriginal Australians are multi-factorial and not yet fully explained. Advanced cancer at diagnosis, reduced completion of cancer treatment, and higher rates of co-morbidities⁷¹ in Aboriginal cases are some of the factors leading to the poorer cancer outcomes recorded. However, differences in socioeconomic status, access to health care (including both screening and treatment services) and lifestyle factors exist.

From a healthcare system perspective, plausible barriers exist at all stages of care. There are few Aboriginal cancer specialists, and non-Aboriginal specialists may have difficulty communicating effectively with patients and their families, potentially leading to paternalistic care and reduced compliance with treatment. Coordinated care between cancer centres, local hospitals and primary care services is essential, but service gaps are commonly reported.⁷²

Several reports suggest that many women do not have a good understanding of the risk of cancer in Aboriginal communities or the mortality from the disease. Research suggests Aboriginal women and their communities commonly regard cancer with a high level of fear and associate the disease with a fatal prognosis. 73,74 This can result in a failure to participate in screening or a delay in seeking medical attention for symptoms, scepticism regarding treatment efficacy, and insufficient community communication about the disease. Embarrassment associated with examination and screening may further hinder early detection, while reduced treatment compliance may in part be due to a shortage of culturally appropriate information concerning treatment options and outcomes. The potentially profound negative impact for a woman of, for example, losing a breast, on her standing in her family and community may also affect treatment compliance. 75



Many clients are uncomfortable in accessing mainstream health services, which may seem threatening and alienating. Communication difficulties can be significant for those who may not have a high level of formal education, and between health care providers, patients and family members. The need to travel to other centres for care can cause financial difficulties, fear, disorientation and dislocation from family. Women may feel unable to make important decisions about treatment in the absence of key family members.⁷⁶

Jacinta Elston (Associate Professor of Aboriginal Health, James Cook University), herself an Aboriginal woman who has experienced breast cancer,⁷⁷ described the practical hurdles for anyone on the cancer journey and explained how they are considerably higher for most Aboriginal people: often no health insurance or income protection, limited understanding of prognosis and treatment options, the absence of an informed community, unfamiliarity with a hospital environment. All of it bewildering, particular for people already at the margins of Australian society.

Some of the barriers and challenges that women face which contribute to inequity in cancer incidence and death rates are issues which are further discussed:

- Socio-cultural, socio-economic and demographic issues
- Effects of colonisation and use of mainstream services
- Poor access to health services and/or transport
- Decision-making about treatment
- Communication
- Communication training
- Few counselling and support services
- Few Aboriginal health workers

Socio-cultural, socio-economic and demographic issues

Socio-cultural, demographic and socio-economic factors may influence cancer treatment patterns and outcomes. An Aboriginal person may not have the financial resources, even with assistance programs, to travel for treatments or to pay for medications; this would likely be compounded by a low rate of private health insurance. Cultural and spiritual barriers may also exist, such as sex of the healthcare provider, religious denomination of the hospital or a preference for traditional healing practices. There may be concerns about how the immediate and extended family will cope with the illness and treatment, especially in areas lacking culturally sensitive aftercare services. Importantly, there may be concerns that treatment is ineffective and not worthwhile.⁷⁸

Aboriginal women were found to have rather different perceptions of the cause and cure of cancer. They gave precedence to family and community needs, which meant that they would only present with symptoms if this did not interfere with their other responsibilities. Women also had different views to practitioners of the relationship between symptoms and the presence of illness.⁷⁹

Factors that underlie Aboriginal and socioeconomic disadvantage in cancer survival, and possibly treatment, go beyond just remoteness of residence and inability to pay. They could include knowledge, attitudes and beliefs about cancer (which may influence presentation for and completion of recommended treatment), communication difficulties, and discrimination on the basis of race or socioeconomic status for access to travel support or more expensive care.⁸⁰



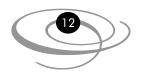
The increased incidence and death rates documented for cancer and other diseases are linked to poor perceptions of health and to social isolation, resulting in withdrawal from community services. Often this withdrawal occurs because people see no real improvement in their own health over the years and can foresee no prospect of change to their health or to the systems that ideally should address their health needs. They have no real resources, either material or human and they have become so disillusioned by prior processes and practices, that it is difficult for this group not to feel indifferent, or apathetic about their health.⁸¹

Effects of colonisation and use of mainstream services

Cancer is a dreaded disease in all societies but for Aboriginal women, it represents an additional threat because having cancer exposes them to what many perceive as the 'colonial mentality' of the Western health care system. There is considerable Australian and international evidence that Indigenous people in formerly colonised counties may distrust government services such as healthcare institutions. The fear of being controlled by white man's hospital system and vulnerable to that authority⁸² is a reason why some women deny their symptoms and/or turn away from medical advice about treatment. Those who avoid cancer treatment choose instead to return to their community where they rely on the resources of local primary health care services. While it is good for the women to be in their own community, local primary health care services and Aboriginal health workers are not sufficiently resourced to provide complex cancer treatment or palliative care for cancer symptoms.⁸³ McMichael, et al, wrote:

Women's treatment decisions are often influenced by family considerations, such as treatment requiring women to be away from their homes and families. Some women are reluctant to place their personal health above the welfare of their children and family, and to leave their community and travel to health services for treatment. Treatment adherence may also be affected by women's understanding and experience of the treatment process. This does not fit with the women's view of health as feeling well and being able to care for one's children or grandchildren. Accordingly, women may choose to discontinue the treatments.⁸⁴

Some Aboriginal women who had received treatment for breast cancer, particularly women from rural and remote areas, found the experience quite isolating and overwhelming. In research conducted by Kong, women indicated that they felt there was little cultural relevance within the system of information provision, diagnosis, treatment and support. ⁸⁵ Cancer often involves multiple modality treatment including a combination of surgery, radiotherapy, and chemotherapy and women are moved between treatment services; many found this disorientating. Aboriginal women often learn for the first time about the treatment for, and prognosis of, cancer in the context of their own disease, and then are overwhelmed with technical information. Women and their families have to understand the diagnosis, take into account information relating to the stages of the disease, and interpret complex information about their prognosis and treatment. They are frequently overwhelmed by the task of coming to terms with the life threatening and 'out of control' nature of cancer. They often associate cancer with death, and so the diagnosis is an especially frightening experience. For many rural and remote women, diagnosis may only be possible if they leave their community to travel to an appropriate service, and so they may lack family support when it is needed most. ⁸⁶



The quality of care that Aboriginal Australians receive from mainstream services varies. Particularly in some country towns, there may be no access to Aboriginal-specific services and Aboriginal patients have to use whatever mainstream services are available, regardless of levels of empathy, expertise or out of pocket expense. Than women from rural and remote areas have limited experience of visiting major regional or metropolitan centres and medical services. Hospitals are described as cold, impersonal and intimidating, and the treatment pathway is rarely regarded as a positive, or even neutral, experience by Aboriginal women. Women with experience in tertiary care centres report being treated by hospital staff in inappropriate, racist or disrespectful ways, and tended to be overwhelmed by the environment. Women also report a lack of a sense of participation and control of their treatment because of their unfamiliarity with the disease, medical procedures and terminology. The participation is a service of their unfamiliarity with the disease, medical procedures and terminology.

Inevitably women see treatment for cancer as a time of great stress. Some lacked confidence that biomedical treatment could effectively save a woman's life, they were sceptical of the advantages of treatment, and frightened of the disfigurement that inevitably occurs with surgery. Some women thought treatment received by Aboriginal people at hospitals was of a lower standard, in part reflecting their views not of cancer-related care, but of the general quality of care delivered to them over the years. ⁸⁹ Dr Prior indicated it would be misleading to conclude that Aboriginal women's hesitancy about cancer treatment and fear of the disease was only on the basis of cultural difference, or a fear of hospitals, because of the association with white man's authority, death, or because cancer treatment separated them from the protection of family and community networks. While all these issues are important influences, at the heart of the fears and misperceptions is the cultural blindness of non-Aboriginal health service staff. Many Aboriginal women report a lack of acknowledgement of cultural difference that distinguished them from non-Aboriginal peoples. ⁹⁰

What the women seek is an approach to cancer treatment that respects their cultural safety and differences by, for example, integrating practices of healing and health care that preserves their integrity as women and acknowledges their role in the family and community. It would be valuable for Aboriginal women to find an harmonious relationship between their cultural values for 'wholeness' and the approach of Western medicine in cancer and palliative health care services. ⁹¹ Michael Dodson, in his Social Justice Commissioner's Report, argues that "good health cannot be 'delivered' to our communities: it must be grown-up and sustained from within, nothing else will work. ... The principle of self-determination is seen as being intrinsically linked to better health". Self-determination for the Aboriginal community is consistent with values of holism, harmony, health and wellbeing. ⁹²

Many Aboriginal people want to remain on their country during their illness and also when they pass away. That doesn't mean they shouldn't have access to treatments that are only available in city hospitals; it means balancing the benefits of the treatment with the potential burdens and considering practical issues such as transport. The health care professional should give the required information so that the patient and their family can make informed decisions.⁹³

Acceptability towards healthcare institutions may be enhanced within Aboriginal medical services, and by improving access to Aboriginal clinical, liaison and interpreter staff in mainstream services.⁹⁴

Poor access to health services and/or transport

Equitable access to health services is essential for all Australians and is of major concern for improving the health of Aboriginal Australians. Some of the many factors that may affect the likelihood of an Aboriginal person attending a facility or using a service when needed include distance from the service; the degree of Aboriginal involvement in the facility; the availability of Aboriginal staff; the level of awareness of issues which impact on Aboriginal health by non-Aboriginal health care professionals, and, in places without permanent services, the frequency with which health care professionals visit. Perceptions about the quality and importance of certain services can also be influential.⁹⁵

A number of barriers continue to restrict Aboriginal people's access to quality health care through mainstream systems. Lack of provision and access to health services in rural and remote communities and in outer metropolitan areas is affected by factors such as the availability of transport. Almost one-quarter (23%) of Aboriginal households did not have ready access to a registered vehicle, compared with 10% of other households, potentially restricting their access to health services. 96,97

Barriers also include poor linkages between different parts of the health system; lack of a population health focus; a limited number and uneven distribution of health care professionals with appropriate skills to address Aboriginal health issues and cultural and social factors such as cultural misunderstandings, poor communication and experiences of discrimination.⁹⁸

Poverty in Aboriginal populations makes it harder to afford private health services and other medical and associated costs. Overall, results from the National Health Survey show that 17% of Aboriginal Australians in non-remote areas had private insurance, compared with 51% of other Australians, reducing the access of Aboriginal people to specialist care.⁹⁹

Aboriginal people living in rural and remote areas are particularly disadvantaged in accessing cancer services, especially radiotherapy. Treatment often requires long periods at or frequent visits to places that are unfamiliar, alienating, often lacking in cultural safety and sometimes seen as overtly discriminatory. The Aboriginal Liaison Officer, if there is one at the treatment institution, is typically over-stretched. There are sometimes problems getting transport assistance for an escort. Transport subsidy schemes are often reimbursed which creates financial difficulties when costs must be met upfront. There are also problems of loss of family support, homesickness and/or boredom for both the patient and their escort if they have travelled to a distant city for longer-term treatment.¹⁰⁰

The availability of bulk-billing is a key factor in Aboriginal access to mainstream services. Any decline in the number of bulk-billing practices will have implications for Aboriginal patients. ¹⁰¹ The Hume region of Victoria encompasses three federal electorates, two of which had the lowest bulk billing rates in Australia – at less than half the national average. Bulk billing was the biggest issue identified in the WHGNE 2003 Purposive Survey and all women of the Hume region are disadvantaged by this. ¹⁰²



Decision-making about treatment

Where illness is not visible or felt, as may be the case with cervical cancer, it is difficult for some women to accept the medical diagnosis or to understand the biological disease process. Perceptions of the absence of pathology present a barrier to women's adherence to screening, but also complicate women's understandings of treatment options. Women may recognise there is an illness, as they may have signs and symptoms such as abnormal vaginal bleeding long before they consult a medical practitioner. In this case, fear of the outcome of "knowing" if there is a disease results in delayed care until the condition is far advanced. 103

There is a dread of the prospect of cancer treatment especially if it involved surgery. The women felt that surgery violated the spiritual as well as physical integrity of the woman's body and consequently her social position as mother, wife or partner. The threat to the woman's body is an important reason why some refuse surgery for breast cancer. Women who had not had cancer predicted that they would refuse radical surgery, in particular a mastectomy, because the breast was a vital part of their 'womanness' and could threaten relationships with their husbands or partners. Some families believe that surgery causes cancer to spread and leads to the patient's early death.¹⁰⁴

In Western societies individuals are considered autonomous decision makers in relation to their health and well-being. Many Aboriginal families make their decisions communally, with family members who have a special, culturally determined role in making decisions. Kin relationships determine not only who makes the decisions, but also who will accompany and support the sick person when they need to be in hospital for diagnosis or treatment and who will look after them later on. In 2005, Oliver wrote:

Aboriginal kinship systems are pretty mysterious to most whitefellas, but we don't need to know the anthropology out of a book. What's more useful is to remember not to make assumptions from our own culture about how things should be done and to get the information needed from the person and their family. There is generally someone who will speak for the family, which is the main link you need. So when important decisions need to be made, the right people need to make them and whitefellas won't necessarily know who these people are. To get it right, you might need to arrange family meetings, and maybe talk by phone or video-link to family members still in their community. ¹⁰⁵

For Aboriginal Australians the importance of kinship and social interdependence in personal identity remains strong ¹⁰⁶. Personal identity is not understood as the identity of one individual. It is always an extended, plural identity. Nonetheless, this is not a denial of individuality. The unique status of every individual is given the security of place and the freedom of expression within their social context. No two people have identical kinship, ritual and spiritual relationships or responsibilities. ¹⁰⁷

There is an epidemic of death in Aboriginal communities. At times the person dealing with cancer has to also deal with loved ones dying around them. Often decisions about treatment, and consent, can be provided only after family consultation, perhaps with interpreters or advocates, and needs to involve the most important family member for that patient. This person often gives the consent and any decision made without their involvement is worthless. The current model of Western health delivery which is based on efficient ward rounds and rapid clinics is not conducive to successful outcomes in Aboriginal people who often require continuity of care, significant involvement of family in slow, deliberate and repeated discussions, with treatment given closer to, if not at, home. 108

Communication

It has been asserted that the vast communication gap that exists between Aboriginal people and the dominant Australian culture affects all aspects of Aboriginal life. Trudgen, in 2006, writes:

In the end, even policies like self-determination fail because of it... I believe this communication gap is the main reason underlying (Aboriginal) people's continual loss of control over their lives. And it is this loss of control, this powerlessness, that manifests itself in the current crisis of health. Someone might ask: 'If it's just a communication problem, why hasn't it been understood before?' The reason is simple. It hasn't been understood because it is a communication problem. The communication gap is cemented into the system so deeply that it is not even noticed by the dominant culture'.¹⁰⁹

With a cancer diagnosis, people are thrown into a new and complex world within which they have to absorb and interpret complex information while coming to terms with the frightening and life-threatening nature of the disease. This is complicated by the language used by health practitioners at diagnostic consultations, which patients find alienating, intimidating and unclear, and treatment outcomes may be poorer for cancer when there are communication difficulties.

The problem of understanding Western medical concepts is also shared by Western consumers of biomedicine where the complexity of medical terminology can be experienced as another language. For Aboriginal people, this fact is exacerbated by the differing understanding of notions of health and healing. The need for cultural safety and understanding begins here. 113

Many women know little about cancer treatment until diagnosis, and as a result of the shock of diagnosis and difficulties in understanding medical advice including terminology and treatment procedures, they are often unclear about their treatment options and efficacy. In research conducted by McMichael, et al, one Aboriginal woman who had a mastectomy said she had not understood her treatment options and recognised neither the term 'mastectomy' nor 'prosthesis'. Another woman said that the consultant who conveyed her diagnosis had not explained to her that the disease could be cured, and she assumed she would die from breast cancer.¹¹⁴

Effective communication and developing trust is critical in supporting patients and their families and carers. ¹¹⁵ It involves a range of areas including health promotion, information sharing, breaking bad news around diagnosis and prognosis, content and strategies for information giving, identification of what patients and families prefer and interdisciplinary communication.

The communication of information is critical to the process of caring for Aboriginal patients and health care staff need to be aware of a myriad of cross-cultural issues. 116 Many Aboriginal people have requirements for successful communication that differ from the general population's, due to cultural beliefs about health and wellbeing that are not perceived or understood by non-Aboriginal providers.

Research shows that rural patients require more information about their impending hospital visit.¹¹⁷ A study examining the experiences of Aboriginal women travelling to hospital noted that none of the women preparing to travel were given information regarding what to expect when admitted to hospital.¹¹⁸

Cultural safety, sensitivity and respect are the key issues in communication with Aboriginal people. Aboriginal culture can bring a multiplicity of views on health and healing; these views needed to be respected, not questioned.¹¹⁹



Communication training

A basic premise of health service delivery is that health staff and patients must be able to communicate effectively in order to achieve sufficient shared understanding for patients to be able to make informed decisions in regard to treatment options and compliance with therapies. Survival of patients with acute and chronic diseases requires an ongoing commitment to treatment by the patient and that commitment is more likely to be made if communication between patient and health practitioner is effective. A shared understanding of issues affecting treatment uptake is essential to optimise management of disease, but there is little opportunity for this to occur when communication between staff and patients is ineffective. It appears that the less patients understand what it is they must do and why, 'the more compliance itself becomes simply an issue of obedience'.¹²⁰

In general terms, using the European philosophical perspective, a clinician is likely to display a preference for information with discrete, static form and meaning, information that is readily gathered, recorded, used and reused. For Aboriginal people, information is contextual; it is shared in the dynamic process of maintaining and strengthening social relationships. The right to information is contingent upon one's place in this process, as determined by gender, kinship and spiritual links. Hence for a clinician, the most successful way to gather and use information is through mutual exchange by participating in the social dynamic.¹²¹

Research has emphasised the importance of providing full information to Aboriginal people so that they are able to make considered decisions about their treatment. The process of giving the full information is referred to as telling the "right story". It is important for the story to be communicated to the appropriate people in the extended family and to people in their community. It is important to allow the time and space for feedback from Aboriginal clients and family to check that they have understood the full facts of the right story.¹²²

The importance of communicating with Aboriginal people through the medium of family meetings cannot be over-emphasised, and if needed, with an interpreter or advocate. Individuals from the extended family can also be called upon to help explain information. Aboriginal people should be allowed to decide the attendance at the family meeting so the right people are there to hear the "right story". Clinical authority needs to be shared with such significant family members.¹²³

Communication training for health care professionals needs to be directed at the undergraduate level and in the work environment. This includes training for health professionals in all sectors such as primary care, community and acute hospitals. Consumers of health care services and many service providers see great need for formal training and occasional re-training in communication skills with patients. Some cancer centres routinely train staff in communication skills but they seem to be the exception. There is a need for improvement in intraprofessional communication skills. Awareness of communication as an issue, and promotion of communication skills programs and what they offer is vital to develop understandings between consumers and clinicians. Cultural safety should be part of all communications training. The potential for misunderstanding is greatest when Aboriginal people are seen only occasionally. One possible way to bring about routine communications training is by including the requirement in the accreditation framework. The need is well known – but the motivation to undertake it seems to be lacking.



Few counselling and support services

From the time of diagnosis, counselling is important to help women and their families adjust. Emotional responses to diagnosis, surgery and treatment include depression, anxiety, confusion, a preoccupation with changes to their health and difficulty with usual role functions. Emotional and practical support during illness is often regarded as the role of family members. However, women are wary of burdening family and friends with their concerns and needs, and may prefer to talk with a professional counsellor who is emotionally removed from the situation. There is little appropriate professional counselling for Aboriginal women and their families, and hence, as one participant explained, "A lot of people mourn in silence. They have got no-one to go to and no-one to talk to and there are quite a few that are really quiet and they don't know how to get around. And they get sicker I reckon if they can't talk". 125

Women want counselling to be available from the time of diagnosis through to the postoperative stages of cancer, especially when they have to travel away from established networks to receive treatment and therefore experience additional stress and loneliness. Mainstream counselling services can meet women's general needs, but they are not always appropriate for Aboriginal people: "She had a support worker but she was white and she didn't want to ring her, didn't want to talk to her. She wanted someone that was from the same culture". Women felt that an Aboriginal counsellor would understand cultural issues and communication styles, and would be easier to relate to. Other women felt it more important that the counsellor have a rapport with, and commitment to, the community, and respect confidentiality.¹²⁶

Few Aboriginal Health Workers

The availability of Aboriginal staff is an important factor in whether or not Aboriginal women are able to effectively access services. ¹²⁷ A glaring gap is the lack of Aboriginal health professionals across the full range of professions, such as nurses, doctors and allied health. ¹²⁸

Mainstream primary health care professionals are often not well equipped to work effectively in a cross-cultural context. Nor are they well equipped to deal with the complex multiple morbidities and specific illnesses that are prevalent in Aboriginal communities. ¹²⁹ Aboriginal health workers (AHWs), therefore, play a pivotal role in the provision of culturally appropriate information and support to the Aboriginal community and mainstream healthcare providers. AHWs are in an ideal position to take a lead role in encouraging women to talk more openly about their fears and concerns related to cancer, and to dispel some of the myths and misinformation that prevent people from getting appropriate screening and cancer care. ¹³⁰

The importance of ensuring an appropriately skilled Aboriginal health workforce and the need for ongoing, culturally appropriate training for AHWs, as well as training in women's health issues for female AHWs has been recognised. The outcomes of several Aboriginal breast cancer initiatives funded by the National Breast Cancer Centre (NBCC) revealed a need for breast cancer education for health workers, including a comprehensive introduction to breast cancer and the issues relevant specifically to Aboriginal women.¹³¹



This was backed up by a survey to investigate oncology clinicians' perspectives on Aboriginal cultural competency. The survey was sent to nearly 800 radiation and medical oncologists and breast surgeons in Australia. There was high recognition of the value of Aboriginal cultural competency training among respondents and strong support for this training to be incorporated into continuing education in their respective specialties.¹³²

Other workforce initiatives have included the establishment of networks to improve communication, respect, empathy and trust between Aboriginal and non-Aboriginal people. Increased collaboration between organisations has strengthened inter-sectoral actions. Aboriginal community-controlled health services have liaised with governments, departments, and organisations within both the Aboriginal and non-Aboriginal communities on matters relating to the wellbeing of Aboriginal communities.¹³³

Importantly, the vocational skills National Health Training Package now includes Aboriginal Health Worker qualifications for the first time, which provides improved career pathways for AHWs both within Aboriginal health work and the broader health industry.¹³⁴

Early Detection and Screening Programs

Aboriginal women are less likely than non-Aboriginal women to participate in early detection programs and are less likely to have cancer found at an early stage, when treatment can be most successful and more options are available.

Demographic characteristics which influence participation in screening for all women include age, marital status, education and socioeconomic status. In one study, race was also identified as a 'risk factor' for never having had a Pap smear. 135

Early presentation is an important part of overall cancer mortality reduction. Aboriginal women tend to present later with symptoms and often end up being managed with more advanced stage disease. 136,137,138 One of the main barriers in Aboriginal people using cancer screening and treatment programs is limited knowledge about the importance of early detection, about their risk of developing cancer, and about their screening and treatment options.

Preventative health behaviour takes low precedence in the daily life of many Aboriginal women, and a strong correlation between cancer and death is perceived. 139 Others did not attend screening because they did not think they were at risk of getting cancer – "it couldn't happen to me". 140

Fear of health screening, fear of cancer, fear of medical authorities and a belief that medical science has no control over the disease form significant barriers to cancer screening for Aboriginal women. Equally significant is the barrier of embarrassment in relation to the test. 141 'Shame' which can result in breach of social rules governing 'women's business', can be a powerful disincentive to participating in screening. 142 For Aboriginal women, shame is not the result of a single encounter or moment that makes them feel uncomfortable, it is an underlying foundation that is connected to a sense of difference that has been imposed on them through much of their lives.

The gender of doctors and other health providers is a potential barrier to cancer screening and treatment. For reasons of modesty, women often prefer to discuss women's health issues with and have procedures performed by a female service provider. Fear of the procedure; embarrassment at being examined internally; misunderstandings of the nature of the test and unpleasant past experiences of such examinations often precipitate or aggravate communication difficulties; and the belief that nothing can be done to prevent cancer are all barriers to cancer screening. Women's personal and sexual histories may also significantly affect their willingness to be examined and to remain in screening programs.

In 2004-05, 29% of all Aboriginal women aged 40 years and over had a mammogram and 49% of all Aboriginal women aged 18 years and over had a pap smear at least once every two years.¹⁴³

Given the medical and social issues often faced by Aboriginal women, cancer screening must be considered in the light of these other priorities. 144,145 Considering the poor health status and high mortality rates in the Aboriginal population of Australia, the prospect of developing programs for screening of specific diseases to allow early intervention and better outcomes appears attractive. However, with painful memories of government policies such as forced assimilation and the stolen generation still very real, Aboriginal people have good reason to be suspicious of activities undertaken by government agencies or their representatives on Aboriginal people "for their own good", particularly if these activities involve surveillance and categorisation. 146 Screening can be an anxiety-provoking exercise for women of any background. Aboriginal women's fears may be intensified through a strong, sometimes inherited, distrust of the Western health care system and government services. 147

The need to formally involve Aboriginal people in service design and delivery applies to cancer screening programs. The mammographic screening program is structured to fit with the Western times of work and work efficiency, which does not take account of Aboriginal values. For example, a woman's social responsibilities may be considered more important than a mammogram appointment. Western and bureaucratic values are reflected in the health system, as women are required to make an appointment for screening at services that mostly operate within normal working hours. 148 In research interviews, Aboriginal women indicated their interest in being able to "drop-in" when they were free, and in having an integrated service that met all women's health needs. 149

Breast Awareness and Screening

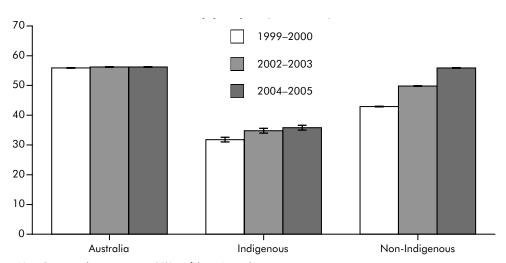
As most women do, Aboriginal women described breasts as symbols of womanhood, sexuality and reproduction and a means by which many nurture their children. These associations are positive. At the same time, breasts are regarded as private. Aboriginal women expressed the view that, in the initial stages of contact with health care staff for breast screening, they would feel "shame" to expose their breasts. For all women, breasts have personal, social and cultural meanings, and these meanings do not disappear when women are asked to remove their shirts and be examined. 151



Early detection of breast cancer involves mammographic screening (X-Ray of breast tissue), breast self-examination and clinical breast examination for the early detection and potential prevention of deaths due to breast cancer in women. BreastScreen Australia (BSA) provides the majority of mammographic screening services in Australia for the early detection and potential prevention of deaths due to breast cancer in women and is the most effective means of early detection. Recently reported the community participation rate of the target population, 50 – 69 year olds, is less than 60%. The target population rate to achieve a noticeable population benefit is more than 70%.¹⁵²

Aboriginal BSA participation in the target age group increased from 30.3% between 1998 and 1999¹⁵³ to 35.8% in 2004-05, but remained lower than for non-Aboriginal women at 56.2%¹⁵⁴ see Table 3. This is largely consistent with national self-reported survey data between 2004 and 2005, which shows 32% of Aboriginal women aged 40 years or more having regular mammograms.¹⁵⁵

Table 3: Participation women aged 50–69 in BreastScreen Australia, by Aboriginal status, 1999–2000, 2002–03 and 2004–05



Note: Bars on columns represent 95% confidence intervals. Source: AIHW analysis of BreastScreen Australia data.

Upon turning 50 years of age, Aboriginal women, like all Australian women who are on the Victorian electoral roll, are automatically invited by letter to attend the BreastScreen Victoria (BSV) Program. It is not currently known how many Aboriginal women are enrolled to vote in Victoria as the Victorian Electoral Commission does not record Aboriginal status.¹⁵⁶

Mammographic-screening participation for Aboriginal women seems to vary by location, perhaps consistent with variations in specific health promotion plans and the quality of Aboriginal identification. An audit of data-collection practices in one BreastScreen programme in Victoria showed that the methods used at that time to collect data on Aboriginal status did not meet best-practice guidelines.¹⁵⁷

In addition to lower initial participation, one study showed that Aboriginal women who attended for initial mammography screening were less likely than non-Aboriginal women to re-attend for routine second-round screening or to continue biennial screening.¹⁵⁸

Considerable effort is required to boost Aboriginal women's mammography participation rates. Effort needs to be made to understand the differing perceptions of health and wellbeing held by Aboriginal women. Priority considerations include the practicalities and cost of access to services, particularly for rural and remote communities, the cultural safety and appropriateness of those services, integration of breast screening with other well women's checks coordinated within primary health care, an enhanced Aboriginal workforce, improved GP responsiveness and reduction of disincentives and the provision of culturally appropriate information to Aboriginal women.¹⁵⁹

Overall throughput (the actual number of women who have attended) and participation rates for Aboriginal women aged 50-69 in the BreastScreen Victoria (BSV) program have increased from 32% (264 screens) in 1995-97 to 48% (532 screens) in 2004-2006. 160

BSV are advocating for Aboriginal women to participate in their program, as evidenced by a week's trial in Robinvale of a drop-in mobile screening service, which was welcomed by the community.¹⁶¹

BSV have undertaken a range of strategies in the recent past. State-wide strategies funded and overseen by the BSV Coordination Unit aimed at Aboriginal women have centred around the Victorian Aboriginal Health Service (VAHS) in Fitzroy. These strategies have predominantly reached Aboriginal women attending the health service and residing in the Melbourne metropolitan, outer metropolitan areas and those visiting from country areas. BSV has funded a full time Aboriginal Health Worker at the VAHS on an annual funding basis since 1997.¹⁶²

At a local level, many BSV services have engaged in specialised recruitment strategies and have established positive relationships with Aboriginal communities and organisations within their catchments. These strategies include: flexible appointment systems/drop-in appointments and group bookings successfully implemented at some services; community and individual familiarisation visits to services; health promotion activities engaging local artists and social groups; attendance/presence at cultural, social and well women's events and other similar relationship building and educational activities. BSV in consultation and partnership with VAHS have produced information resources specifically aimed at Aboriginal women, including brochures, a flipchart and a DVD.¹⁶³

Aboriginal participation overall at Maroondah BreastScreen sites in 2005 to 2007, is shown in Table 4 contrasted with overall participation of the Mobile Screening Service (MSS) while it was in the Hume region of Victoria in 2006.¹⁶⁴



Table 4: Aboriginal participation at all Maroondah BreastScreen sites 2005-07, contrasted with general participation at MSS in Hume region 2006

Aboriginal participation overall at Maroondah BreastScreen sites 2005-07, contrasted with overall participation MSS Hume region Victoria 2006

Dates of Target age group, 50-69 years of age					
Localities			i i		
	service	Population	Throughput	Participation	
Women who identified as	2005-2007	Aboriginal	Aboriginal	Aboriginal	
Aboriginal in		1660	539	32%	
ALL of Maroondah BreastScreen sites					
Wangaratta area including, Whorouly, Barnawartha,	1/8/06 to 8/12/2006	General population	General population	General population	
Beechworth, Glenrowan, Rutherglen		4627	2257	49%	
Yarrawonga & district	2/3/06 to 7/4/2006	1078	687	64%	
Myrtleford area including, Bright, Yackandandah, Tawonga, Mt Beauty, Mt Buffalo	20/6/06 to 21/7/2006	1878	783	42%	
Tallangatta , Mitta Mitta, Charleroi	30/5/06 to 8/6/2006	373	86	23%	
Corryong , Cudgewa. Burrowye	16/5/06 to 26/5/2006	341	201	59%	

Notes: Population refers to overall population taken from census data; throughput, the actual number of women who have attended; participation in percentage terms; localities includes a sampling of the catchment which attended each MSS.

Aboriginal BreastScreen participation is significantly lower than the total population participation in 2005-2007 at Shepparton (Hume region, Victoria), as shown in Table 5. Shepparton is a fixed screening site within the St Vincent's BreastScreen area.¹⁶⁵

Table 5: Aboriginal BreastScreen participation at Shepparton and total population participation 2005-07

Population	Dates of	Target age group, 50-69 years of age		
ropulation	service	Population	Throughput	Participation
Aboriginal	July 2005 to June 2007	122	34	28%
Total population	July 2005 to June 2007	11,182	6784	60%

Notes: Population is from Census data, throughput is BreastScreen actuals; Localities accessing this service include the districts of Shepparton, Tatura, Kyabram, Numurkah, Nathalia, Violet Town, Benalla, Cobram, Tungamah, Katunga, Dookie and others; St Vincent's BreastScreen service advises that the 'ATSI data is at best approximate as the census figures are not highly reliable and we also know anecdotally that Aboriginal women often do not identify as such in their personally recorded history'. 166

The environment in which health services are delivered influences women's experience and their likelihood to present a second time. In one study, women who had presented at a BreastScreen service in Queensland were generally satisfied, described staff as pleasant, and felt the radiographers had explained the screening process clearly. However, women were often critical of the location of relocatable or mobile services, and emphasised the need for services to be central and easily accessible for women who lacked access to public or private transport. Women saw the fixed appointment system as a major barrier to Aboriginal women attending screening, conflicting with 'Aboriginal time' and precluding the possibility of women 'dropping in' for screening.¹⁶⁷

BreastScreen Victoria has identified some other barriers to participation in breast cancer screening programs for Aboriginal women as: 168

- lack of information, education and understanding around complex health messages
- cultural beliefs about health and disease causation
- perceptions about health priorities and a 'wellness' program aimed at secondary prevention in the context of a community experiencing acute health issues such as diabetes, substance abuse, sexual abuse, domestic violence and sexually transmitted diseases
- limited time available to engage in preventative health behaviours due to family responsibilities, availability of childcare, alternate and appropriate care for Elders and dependent relatives
- services available are culturally unsuitable and at odds with the Aboriginal holistic view of health
- rigidity of appointment systems; opportunities to screen may present only sporadically and spontaneously for some rural Aboriginal women
- conspicuous nature of the location of BreastScreen Services may be a deterrent
- unfamiliarity with surroundings and the service's physical space.

Cervical Screening

With regular biennial Pap smear screening and appropriate follow-up and treatment, up to 90% of the most common forms of cancer of the cervix can be prevented. A lack of screening for precancerous lesions and infection with carcinogenic human papilloma virus (HPV) are risk factors for cervical cancer.

Internationally, cervical cancer prevention programs based on cytological surveillance have been amongst the most successful public health achievements in modern history. Almost all developed health jurisdictions have implemented successful screening programs. Australia now has the lowest mortality and second lowest incidence in the developed world.¹⁷¹ It is of concern that these interventions appear not to have had as marked a benefit for Aboriginal women despite early detection being the cornerstone to reducing cervical cancer mortality.¹⁷²

Barriers to accessing cervical screening are often exacerbated for Aboriginal women, which leads to excess mortality of Aboriginal women from cervical cancer. Barriers include lack of access to GPs and female health care professionals, poor transport, lack of child care, difficulty getting time off work, financial problems, lack of understanding or confusion about Pap smear procedures. Many Aboriginal women also experience fear and embarrassment about the procedure. This is particularly so if there is prior history of sexual abuse, or if they believe the Pap test is a screening tool for sexually transmitted infections (STI) due to the associated stigma of being diagnosed with an STI .^{173,174}



Given that Aboriginal women in Australia are far less likely than non-Aboriginal women to attend regularly for Pap screening, it might be expected that perceptions of the procedure among the two groups would differ markedly. In a study carried out among both Aboriginal and non-Aboriginal Australians living in South East Queensland, it was found that in most cases, both groups of women talked about exactly the same issues. Fear of cancer and embarrassment were the greatest barriers against Pap testing. Aboriginal women fear cancer for all the same reasons as non-Aboriginal women, however their fear is intensified through a powerful, sometimes inherited distrust of the Western medical institution which is a further inhibition to their participation in screening. ¹⁷⁵

Cancer in the Aboriginal population

Diagnosis, Incidence, Mortality and Survivorship

The most common cancers diagnosed among Aboriginal women in 2000-2004 were breast cancer (25%), cancer of the lung, bronchus and trachea (12%), colorectal cancer (9%), cancer of the cervix (7%) and cancer of unknown primary site (6%). In contrast to the non-Aboriginal population, more new cases of cancer were reported among Aboriginal women (1,598) than Aboriginal men (1,485) in this period.¹⁷⁶

Reflecting the relative youth of the Aboriginal population, the median ages at diagnosis were much younger for Aboriginal than non-Aboriginal women, 55.4 compared with 65.7.

Aboriginal people with cancer were more likely to be diagnosed with disease that had spread beyond the tissue or origin than non-Aboriginal people¹⁷⁷ and the proportion of cancers for which the primary site was unknown has been recorded as much higher for Aboriginal people.¹⁷⁸

The reported total incidence of cancers in the Aboriginal population is below that of the general population, probably influenced in part by the youth of the population and underreporting.¹⁷⁹

The Victorian Cancer Registry (VCR) records an average of 30 new cancers in persons identified as Aboriginal each year, with the leading sites in Victorian Aboriginal women noted in Table 6.¹⁸⁰

Table 6: Leading sites of cancer in Victorian Aboriginal women 2000-2005

Leading sites of cancer in Victorian Aboriginal women			
New cases in 6 years 2000-2005			
Cancer site/type	Number		
Breast	34		
Lung	11		
Bowel	9		
Unspecified site, head & neck, Melanoma, Leukaemia, Lymphoma and Other with < 1 case per year	38		
Total	92		

Data in Table 7 is reported by the Victorian Department of Human Services Integrated Cancer Services (ICS) regions¹⁸¹. Hume Region has 18.5% of the total new cancers – the highest in the State.

Table 7: New cancers identified in Aboriginal people by DHS ICS regions 2000-2005

New cancers identified in Aboriginal people by Department of Human Services (DHS) Integrated Cancer Services (ICS) regions				
New cases in 6 years 2000-2005				
Integrated Cancer Services region	Total male and Female	% of total		
Hume RICS (excluding Albury)	32	18.5		
Southern MICS	25	14.5		
Western & Central MICS	20	11.6		
North-Eastern MICS	27	15.6		
Barwon RICS	9	5.2		
Grampians RICS	12	6.9		
Loddon-Mallee RICS	31	17.9		
Gippsland RICS	17	9.8		
Total	173 (93 female)	100.00%		

The past two decades have seen a 30% reduction in cancer mortality rates in Australia, yet these successes have not been shared by Aboriginal people. Deaths from cancer in Aboriginal Australians are generally much higher than expected, at nearly two^{182,183,184,185,186} to four times¹⁸⁷ the rate of other Australians with cancer. Cancer was the cause of 17% of all deaths reported for Aboriginal Australians in 2004.¹⁸⁸ The median ages at death from cancer were much younger for Aboriginal than non-Aboriginal people, 63.8 years compared with 72.0 years for women.¹⁸⁹

The five-year cancer survival rate is the proportion of people with cancer who are still alive five years after their cancer was diagnosed, and is often an approximate indicator of disease cure rates. There are very large differences in cancer survival between Aboriginal Australians and other Australians, but unlike cancer incidence, where Aboriginal people have a relative advantage for several cancer sites, Aboriginal survival is worse than that for non-Aboriginal people for almost all cancer sites. 190,191,192

It appears that for cancer sites where all Australians have poor survival, Aboriginal Australians suffer little or no survival disadvantage. However, for cancer sites where most Australians can expect a medium to high probability of surviving 5 years or more, Aboriginal Australians appear to be at a considerable disadvantage. ¹⁹³ For example, 5-year Aboriginal survival for thyroid, breast, and cervical cancer was 69%, 56%, and 37%, respectively, compared with 95%, 85%, and 79% for all Australians combined. ¹⁹⁴ These cancers can be amenable to early diagnosis, effective treatment and a high probability of cure. Better access to, and higher quality of health care offers the possibility of disease cure for many Aboriginal people with these cancers. ¹⁹⁵ Early detection is less likely for Aboriginal than non-Aboriginal women, and Aboriginal women are less likely to have access to and/or receive or complete treatment. Because of the late stage of cancer at diagnosis, Aboriginal women are therefore more likely to require radical surgery for treatment. All these factors impact on survival rates.



The South Australian Cancer Registry undertook a detailed analysis of the issue of survivorship. It found that late stage diagnosis was only part of the explanation for lower Aboriginal survival rates. Other factors are involved and these may include choice of curative or non-curative treatment, delays in treatment or incomplete treatment, or the presence of other chronic diseases such as diabetes or heart disease which make Aboriginal people less likely to survive major surgery and the complications of chemotherapy and radiotherapy. 196,197

Specific cancers

Table 8: Aboriginal women in Australia (unless stated otherwise)

Cancer	Diagnosis (2004-5) % ¹⁹⁸	Incidence rate Per 100,000 (2005)	Hospitalisation rate 2005-2006 ¹⁹⁹	5-year Survival rate ²⁰⁰	Mortality rate
Breast	25	27.7 201	140	56%	27 per 100,000**
Lung, bronchus and trachea	12	15.1 (Lung only)	112	*	21% of cancer deaths
Colorectal	9	9	*	*	*
Cervix	7	^16.9 ²⁰³	84	37%	8.3 per 100,000***
Unknown primary site	6	*	*	*	*
Uterine	*	8.7	*	*	*
Secondary cancer of other sites	*	*	60	*	*
Thyroid	*	*	*	69%	*

^{*}Missing data

^{**}in NT, SA, WA and Qld

^{***}For the jurisdictions of Qld, WA, SA and the NT, the age-standardised mortality rate attributable to cervical cancer among Aboriginal women aged 20–69 years in the 2002–2005 period was reported to be 8.3 deaths per 100,000 women, more than four times as high as the rate of 2.0 deaths per 100,000 women for other Australian women in the same age range²⁰⁴

²⁰⁰ 5-year Aboriginal survival for thyroid, breast, and cervical cancer was 69%, 56%, and 37%, respectively, compared with 95%, 85%, and 79% for all Australians combined

[^] In 2000–2004, despite under-reporting, cervical cancer incidence in Aboriginal women was 16.9 new cases per 100,000 women for NSW, Vic, Qld, WA and the NT combined, more than double the non-Aboriginal rate of 7.1 new cases per 100,000 women.

Breast Cancer

The little data comparing Aboriginal and non-Aboriginal women suggests that at the population level, Aboriginal women may be at less risk of breast cancer. There is evidence that this may reflect overall differences in reproductive history. The literature points to a number of protective factors, including early pregnancies, multiple pregnancies and possibly longer duration of breast feeding. Reproductive factors including having fewer or no children and having children later in life are linked with higher rates of breast cancer at the population level, though increase in relative risk from all these factors is quite small. Aboriginal women tend to begin having children at a much younger age and have much higher fertility rates under 25 than do other women in Australia. In 2003, the teenage (15-19 years) birth rate among Indigenous women was more than four times the overall Australian teenage birth rate. The peak age group for births to Indigenous women was 20-24 years (133 babies per 1,000), compared with 30-34 years for all women (113 babies per 1,000). Similarly, Aboriginal women tend to bear more children than non-Aboriginal women. In 2003, the total fertility rate for Aboriginal women was estimated to be 2.15 babies, compared with 1.76 babies in the total Australian female population.

When the limited data on breast cancer in Australian Aboriginal communities is combined with the fact that Aboriginal background is likely to be under-recorded on all the relevant forms, the best conclusion appears to be that the incidence rates from breast cancer may be slightly less for Aboriginal women, but rates of hospitalisation appear to be lower and mortality appears to be higher.²¹¹

Breast cancer is the second leading cause of cancer deaths in Aboriginal women²¹² (after lung cancer) with mortality from breast cancer 9% higher than for the Australian female population.²¹³

In 2004, breast cancer was both the most common cancer diagnosed and the most common cause of cancer death amongst Australian women.²¹⁴ There has, however, been a long standing but erroneous belief that breast cancer is not an important cancer amongst Aboriginal women²¹⁵ and that the young age profile of the Aboriginal population is such as to reduce the importance of breast cancer, as it is a disease primarily of older women. According to the ABS there are more than 23,000 Aboriginal women aged 40 and over. This belies the often claimed notion that the age profile of the Aboriginal population reduces the importance of breast cancer.^{216, 217}

It is estimated that there may be approximately sixty new cases of breast cancer per year among Aboriginal women,²¹⁸ who tend to present with larger cancers (32mm vs. 23 mm) and more lymph node involvement (60% vs 35%), than other Australian women.²¹⁹

Cervical cancer

Reductions in cervical cancer have occurred amongst Aboriginal women, but both incidence and mortality rates remain considerably higher than national rates.^{220, 221} Australian women who are at increased risk of developing a medically unusual growth of the cervix include those who live in a rural area, identify as Aboriginal or come from a non-English speaking country.²²²



In 2000–2004, despite under-reporting, cervical cancer incidence in Aboriginal women was 16.9 new cases per 100,000 women for NSW, Vic, Qld, WA and the NT combined, more than double the non-Aboriginal rate of 7.1 new cases per 100,000 women.²²³

For Qld, WA, SA and the NT, the mortality rate attributable to cervical cancer among Aboriginal women aged 20–69 years in the 2002–2005 period was reported to be 8.3 deaths per 100,000 women, more than four times higher than the rate of 2 deaths per 100,000 women for other Australian women in the same age range.²²⁴

In Aboriginal women, deaths due to cervical cancer occur at a younger age than in non-Aboriginal women. Over the period 1986-1997, the mean age at death from cervical cancer for Aboriginal women was 52.8 years – significantly lower than the 61.7 years for non-Aboriginal women.²²⁵ Table 9 details mortality rates by age, and shows that Aboriginal women have much higher rates of death from cervical cancer in most age brackets.²²⁶

Table 9: Age-specific and age-standardised mortality rates for cervical cancer, by 5-year age group and Aboriginal status Qld, WA, NT & SA 2002-2005

Age-specific and age-standardised mortality rates of cervical cancer by 5-year age group and Aboriginal status Qld, WA, NT & SA 2002-05				
	Aboriginal Australians	Other Australians		
Age group (years)	Number of deaths per 100,000 women	Number of deaths per 100,000 women		
30-34	4.2	1.4		
35-39	2.5	0.07		
40-44	14.4	1.9		
45-49	3.8	2.7		
50-54	23.6	3.4		
55-59	7	2.4		
60-64	0	3.7		
65-69	41.3	4.9		
70-74	41.2	4.8		
75+	49.4	10.7		

The risk of death from cervical cancer for Aboriginal women compared with non-Aboriginal women increases from approximately four times for women in metropolitan areas through nearly 10 times the risk for rural women to 18 times the risk for women in remote areas. Compared with Aboriginal women living in metropolitan areas, Aboriginal women living in a rural or remote area have approximately twice the chance of dying from cancer of the cervix.⁴

⁴ While there are limitations in the data, largely due to potential misclassification bias in either death or population data, the magnitude of the differences in risk found and the effect in relation to rurality indicate that the findings are valid.



Lung cancer

Smoking rates in the general Australian population have been declining for many years, yet smoking is more prevalent in Aboriginal populations aged 14 years and over (39%-50%) than non-Aboriginal populations (20%).^{227, 228}

Between 1999-2003 lung cancer was responsible for 21% of Aboriginal female deaths from cancer.²²⁹

These is a correlation between living in a rural or remote area and the increased prevalence of lung, head, neck, and lip cancer which are all smoking related cancers. There may be higher rates of smoking among both the Indigenous and non-Indigenous populations in remote and very remote areas that lead to increased rates of smoking-related cancers in these areas.²³⁰

Whilst this disease is invariably associated with a poor prognosis, lung cancer is detected earlier among Aboriginal patients than non-Aboriginal patients, compared to other types of cancer. There is a hypotheses this is because more Aboriginal Australians frequently undergo chest X-Rays and other clinical investigations for chronic respiratory diseases, such as Tuberculosis (TB), which is more prevalent among Aboriginal communities than non-Aboriginal ones, thus enabling earlier detection of any asymptomatic malignancies that may be present.²³¹

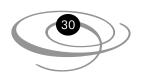
Conclusion

Despite the limited available data on cancer in Australian Aboriginal populations, and the varying quality of such data, cancer is clearly an important health issue for Aboriginal people. Aboriginal and non-Aboriginal Australians appear to be at a broadly similar risk of cancer, but Aboriginal patients are much more likely to die from the disease. Although Aboriginal people are less likely to have some types of cancer, they are significantly more likely to have cancers that have a poor prognosis, such as lung and liver cancer. The prognosis of Aboriginal patients is compromised by inadequate screening rates, more advanced stages at diagnosis and less likelihood of receiving adequate and appropriate cancer treatment.

Barriers to diagnosis, treatment and care can be addressed by improving the quality and appropriateness of health care and counselling services for Aboriginal women and their families and by increasing women's awareness of cancer.

If programs are to be effective in improving cancer outcomes for Aboriginal women, they need to be holistic and not focus on cancer in isolation from other health issues. Programs would ideally be accessible to Aboriginal women wherever they live, and would be delivered where possible by women. Health promotion could focus on increasing understanding among Aboriginal women about their risk of cancer, the benefits of preventative health behaviour and the importance of early detection.

Aboriginal women experiencing cancer often find it difficult to get adequate information about treatment options, feel that their treatment is not culturally appropriate, encounter practical difficulties in travelling for treatment and cannot access adequate supportive care.



In order to make sound treatment decisions, the health professional must understand the need to work with appropriate family members, and must give weight to the wishes of many Aboriginal patients to remain on their traditional country. Such issues can be exacerbated in the context of a resource-poor care environment.²³²

Many women perceived the locus of control for improving health care and health status as lying with health practitioners and governments bodies. However, a number of women are calling for increased community participation in health care services. This supports the National Aboriginal Health Strategy, which said that community control of health programs was crucial to the wellbeing and health of Aboriginal communities. Improved screening, detection and treatment for cancer and the care of women with the disease requires health practitioners to better serve the needs of Aboriginal people and Aboriginal people to take an active and participatory role in their own health and health care.

Recommendations

1. Complete a mapping of regional and state services and resources

Before determining more definitive recommendations and action plans, it is necessary to know what resources and services are available at a local, regional and state level. Breast Cancer Network Australia (BCNA) has completed some work towards mapping Aboriginal resources around the country.

- 1.1 It is recommended that this BCNA document be examined to determine its completeness for our region. If necessary, WHGNE with BreaCan, Hume RICS and the Victorian Aboriginal Health Service could partner to undertake further mapping to determine what is available specifically for Aboriginal women and their families regarding screening and cancer services within Victoria and more specifically the Hume region.
- 1.2 It is recommended that the service mapping include supportive and palliative care and that this report informs and inspires Hume Region Palliative Care and others to enhance their services and adopt culturally safe practices.

2. Enhance cancer-related health services to Aboriginal women

Improve health promotion for Aboriginal women in regard to cancers, and improve health services for Aboriginal women experiencing cancer in rural areas. This ranges from health education and health promotion to public health programmes such as screening, primary care, and specialist curative and palliative services.

- 2.1 It is recommended that health planners and service providers:
 - involve Aboriginal women and local Aboriginal communities in advising on improvements to health promotion and cancer-related services
 - recognise that extended family and social support mechanisms are vital to recovery
 - adapt mainstream services to be culturally safe and appropriate for Aboriginal people
 - address grief and loss issues for women and their extended family, kinship groups and decision-makers
 - consider research findings such as the recommended steps in providing psychosocial support to Aboriginal women with cancer (See Appendix 1)

3. Increase health promotion for early detection, screening and risk factors

The National Breast and Ovarian Cancer Centre have developed Well Women Workshops to provide Aboriginal women with information every woman should know about breast cancer.

3.1 It is recommended that a partnership be developed between WHGNE, Aboriginal Health Services, Cancer Council Victoria, Hume RICS, BreaCan and NBOCC to deliver these workshops in Hume region. Participants could include Aboriginal women, local health workers, BreastScreen staff and Aboriginal breast cancer survivors and opportunities would be made to share stories of strength and survival.

With half of Aboriginal adults being daily smokers, and no evidence of any measurable decrease in smoking over the past decade, it is apparent that tobacco-control programmes up to now have been inadequate and ineffective.

3.2 It is recommended that anti-smoking campaigns and health promotion programs address the social and cultural role of smoking amongst Aboriginal people.

Improving participation in Pap tests and breast screening and follow-up would prevent many deaths from breast and cervical cancer.

3.3 It is recommended that local agencies and Aboriginal health services develop partnerships with PapScreen and BreastScreen Victoria to promote and provide more culturally appropriate pap screens and mammograms as part of a holistic women's health program.

4. Increase numbers of Aboriginal health professionals

4.1 It is recommended that more Aboriginal health professionals be employed in women's cancer-related services in the Hume region.

5. Offer specific professional development regarding Aboriginal women and cancer

There is an identified need amongst Aboriginal and non-Aboriginal health workers for a comprehensive introduction to breast cancer, including information about incidence in Aboriginal women, symptoms, early detection, treatment and supportive care.

- 5.1 It is recommended that WHGNE partner with NBOCC, CCV, Hume RICS and Aboriginal Health Services to offer women's cancers training in the Hume region to support health care professionals.
- 5.2 It is recommended that WHGNE partner with Cancer Council Victoria, Hume RICS and Aboriginal Health Services to offer culturally safe communication skills training sessions for Hume region health care professionals to better serve Aboriginal patients and their families.
- 5.3 It is recommended that the TAFE and employment sectors undertake further exploration of the National Competency Standards for Indigenous Health Workers to determine how these can be applied within the region.



6. Cultural Safety

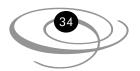
- 6.1 It is recommended that health providers offer their staff cultural training so that Aboriginal women feel trust in the health organisation and feel valued by those organisations.
- 6.2 It is recommended that, wherever possible, Aboriginal clients with gender-specific health problems be treated by a health professional of the same sex.
- 6.3 It is recommended that Hospital Boards, Community Health Service Boards and the boards of other organisations invite Aboriginal women to become active members.

Appendix 1

Recommended steps involved in providing psychosocial support to Aboriginal people with cancer ²³³

Abridged from: NBCC & NCCI National Breast Cancer Centre and National Cancer Control Initiative. 2003, Clinical practice guidelines for the psychosocial care of adults with cancer, National Breast Cancer Centre, Camperdown NSW.

- Recognise that there is great diversity among communities in terms of culture and societal obligations
- Be aware of the importance of potential conflicts between illness and treatment and a patient's social and spiritual obligations
- Use Aboriginal health and community services to help provide information and support and to interpret and advocate for the patient
- Provide women with access to a female medical professional or nurse, when possible
- Explain how confidentiality is achieved within the medical setting
- Direct questioning and eye contact may be difficult for many people
- Assess the person's understanding of their disease, treatment and prognosis
- Offer to discuss issues and treatment options with the patient's family and involve them in decision-making
- Explain the importance of social support and encourage the person to seek support from family, friends, support services and local cancer organisations
- Provide written information in a culturally appropriate way, if available
- Arrange follow-up and support.



Appendix 2

Cancer in rural and regional Victoria

In rural and regional Australia, the problems of diagnosing and treating cancer reflect disadvantages across the healthcare spectrum experienced by these communities. Improved cancer care should be a rural health policy and service priority as its impact is felt disproportionately in regional areas. The evidence indicates that reducing inequality in cancer outcomes requires a combination of improved primary healthcare and access to specialist multidisciplinary services.²³⁴

Survival of cancer was highest among women living in major city areas with highest socioeconomic status.²³⁵ The five-year prevalence of cancer survivors of 1,555 per 100,000 population living in areas of the highest quintile of socioeconomic status in Australia was higher than that for other quintiles because of their significantly higher survival. Associated with this higher survival was the fact that in 2000–2004, 95% of persons with cancer in this socioeconomic status quintile resided in major cities and therefore would have had greatest access to ongoing screening and treatment services. In contrast, the five-year prevalence was 1,332 per 100,000 for the 20% of persons with cancer living in areas of the lowest quintile of socioeconomic status in Australia. This population of cancer sufferers had the lowest survival and only 57% of them were living in major cities at the time of diagnosis.²³⁶

For women, the cancers that had the greatest difference in 5-year relative survival between the lowest and the highest socioeconomic status quintiles were:

- cervical cancer (65% in the first quintile and 78% in the fifth quintile)
- colorectal cancer (59% in the first quintile and 67% in the fifth quintile)
- breast cancer (86% in the first quintile and 90% in the fifth quintile). 237

There were a total of 1501 new cancer cases diagnosed in the Hume region of Victoria in 2006. Of the five most common types of cancer in the Hume region in order of incidence, breast was third in number, following from prostate and colorectal.²³⁸

The Local Government Areas (LGAs) which have the five highest number of cancer cases in Hume region²³⁹ are shown in Table 10. According to Victorian Cancer Registry data, there were a total of 536 deaths recorded as a result of cancer in the Hume region in 2005.²⁴⁰

Table 10: LGAs with the five highest cancer incidence rates, Hume region Victoria

Local Government Area (LGA)	New cancer cases 2006
Greater Shepparton	315
Moira	218
Wangaratta	162
Mitchell	162
Wodonga {excluding Albury, NSW}	135

Gynaecological cancer incidence HRICS Region and GSAHS NSW

The Cancer Epidemiology Centre at Cancer Council Victoria has supplied the gynaecological cancer incidence in the Hume Regional Integrated Cancer Services (HRICS) Region for the period 2002-2004,²⁴¹ and the NSW Health & Cancer Institute sites figures for Greater Southern Area Health Service (GSAHS) NSW for 2002-2006²⁴² in Table 11.

Table 11: Gynaecological cancer incidence Hume RICS Region 2004-2006 and GSAHS 2002-2006 by cancer type and LGA of usual residence

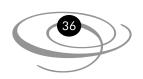
Gynaecological cancer incidence in the Hume RICS Region 2004-2006 and Greater Southern Area Health Service 2002-2006 by cancer type and LGA of usual residence						
Local Government Area (LGA) Victoria	Cervix	Uterus	Ovary	Placenta	Vulva etc	All gynae
Alpine Shire	-	5	-	-	-	8
Benalla Rural City	-	-	-	-	-	6
City of Greater Shepparton	-	13	5	-	-	22
Indigo Shire	-	8	′-	-	-	14
Mansfield Shire	-	-	-	-	-	2
Mitchell Shire	-	8	7	-	-	17
Moira Shire	-	10	8	-	-	18
Murrindindi Shire	-	8	-	-	-	15
Strathbogie Shire	_	-6	-	-	-	8
Towong Shire	-	-	-	-	-	3
Wangaratta Rural City	-	12	9	-	-	28
Wodonga Rural City	-	5	5	-	-	13
Albury crude estimate		14	14			36
Total Hume RICS	25	91	60	0	15	190
Greater Southern Area Health Service NSW (2002-2006)						471

Where there were <5 cases; numbers are not shown

Breast cancer incidence in 2004-2006 for women resident in the Hume Regional Integrated Cancer Service (HRICS) region,²⁴³ and Albury and Greater Southern Area Health Service NSW from 2002-2006²⁴⁴ is shown in Table 12.

Table 12: Breast cancer incidence 2004-2006 for women resident in HRICS region, and Albury and GSAHS NSW 2002-2006

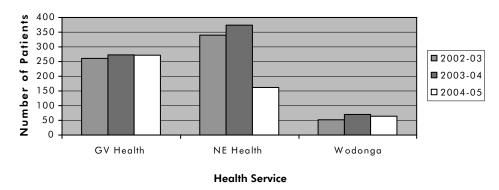
Local Government Area - Hume RICS (Victoria)	Average new breast cancer cases per year
Alpine Shire	10
Benalla Rural City	11
City of Greater Shepparton	35
Indigo Shire	8
Mansfield Shire	4
Mitchell Shire	18
Moira Shire	26
Murrindindi Shire	10
Strathbogie Shire	9
Towong Shire	3
Wangaratta Rural City	16
Wodonga Rural City	14
Albury	26
Greater Southern Area Health Service (NSW)	281



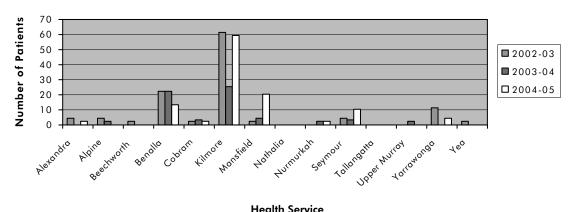
Breast cancer separations in Hume region by health service and year²⁴⁵ are defined in Table 13.

Table 13: Breast cancer separations Hume region by health service & year

Breast Cancer Separations



Breast Cancer Separations



Health Service

Gynaecological cancer incidence HRICS Region and GSAHS NSW

The Cancer Epidemiology Centre at Cancer Council Victoria has supplied the gynaecological cancer incidence in the Hume Regional Integrated Cancer Services (HRICS) Region for the period 2002-2004,²⁴⁶ and the NSW Health & Cancer Institute sites figures for Greater Southern Area Health Service NSW for 2002-2006²⁴⁷ in Table 14.

Table 14: Gynaecological cancer incidence Hume RICS Region 2002-2004 and GSAHS 2002-2006 by cancer type and LGA of usual residence

Gynaecological cancer incidence in the Hume RICS Region 2002-2004 and Greater Southern Area Health Service 2002-2006 by cancer type and LGA of usual residence						
Local Government Area (LGA) Victoria	Cervix	Uterus	Ovary	Placenta	Vulva etc	All gynae
Alpine Shire	-	5	-	-	-	14
Benalla Rural City	-	-	-	-	-	8
City of Greater Shepparton	-	13	9	-	-	28
Indigo Shire	-	5	5	-	-	12
Mansfield Shire	-	-	-	-	-	4
Mitchell Shire	-	7	7	-	-	16
Moira Shire	-	8	11	-	-	23
Murrindindi Shire	-	-	-	-	-	8
Strathbogie Shire	-	-	-	-	-	9
Towong Shire	-	-	-	-	-	7
Wangaratta Rural City	-	6	ı	-	-	16
Wodonga Rural City	-	9	5	-	-	21
Albury crude estimate		23	13			52
Total Hume RICS	22	90	71	2	17	218
Greater Southern Area Health Service NSW (2002-2006)			·			471

Where there were <5 cases; numbers are not shown

Breast cancer incidence in 2002-2004 for women resident in the Hume Regional Integrated Cancer Service (HRICS) region,²⁴⁸ and Albury and Greater Southern Area Health Service NSW from 2002-2006²⁴⁹ is shown in Table 15.

Table 15: Breast cancer incidence 2002-2004 for women resident in HRICS region, and Albury and GSAHS NSW 2002-2006

Local Government Area - Hume RICS (Victoria)	Average new breast cancer cases per year
Alpine Shire	12
Benalla Rural City	8
City of Greater Shepparton	28
Indigo Shire	5
Mansfield Shire	5
Mitchell Shire	23
Moira Shire	14
Murrindindi Shire	9
Strathbogie Shire	10
Towong Shire	3
Wangaratta Rural City	20
Wodonga Rural City	17
Albury	26
Greater Southern Area Health Service (NSW)	281



Endnotes

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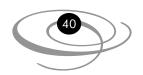
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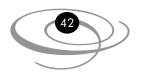
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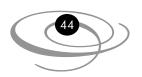
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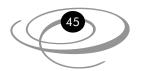


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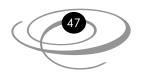
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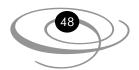
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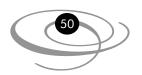
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