Submission
No 35

INQUIRY INTO OVERCOMING INDIGENOUS DISADVANTAGE

Organisation: The Cancer Council NSW

Name: Ms Britt Granath

The Cancer Council
New South Wales

Building a
Cancer Smart
Community

30 January 2008

Ms Rachel Simpson
Director
Standing Committee on Social Issues
Parliament House
Macquarie St
Sydney NSW 2000

Dear Ms Simpson,

Inquiry into Closing the Gap: Overcoming Indigenous Disadvantage

The Cancer Council NSW welcomes this opportunity to provide a submission to the Standing Committee on Social Issues' inquiry into Indigenous disadvantage. The Cancer Council NSW is the leading cancer charity in NSW. Our mission is to defeat cancer. The Cancer Council NSW envisages a future where no life is cut short or its quality diminished by cancer.

Cancer is the second highest cause of death, after cardiovascular disease, in Indigenous people. Although cancer survival in NSW is now amongst the highest in the world for the general population; Indigenous people and other disadvantaged groups are being left behind. Several preventable cancers such as lung cancer, bowel cancer and cancer of the cervix, occur more frequently in Indigenous people than in other Australians. Indigenous Australians with cancer are more likely to die from their disease; cancer-related mortality rates are 1.7 times higher for Indigenous males, and 1.6 time higher for Indigenous females compared with the non-Indigenous population.

Several issues which influence the high cancer mortality in Indigenous people have been brought to the attention of The Cancer Council NSW during commissioned research and community consultation. These include the high rate of cigarette use, low participation in population-based cancer screening programs and difficulties in accessing health related transport of Indigenous people. In addition, despite the high standard of reporting for cancer notification for the general population; data are not adequately collected by the State Government on cancer incidence and mortality of Indigenous people.

153 Dowling Street
Woolloomooloo NSW 2011
PO Box 275 Kings Cross NSW 1340
T: (02) 9334 1900
F: (02) 9358 1452
www.cancercouncil.com.au
ABN 51 116 463 846

…1/2

As cancer is a significant contributor to mortality in Indigenous people, with cancer-related survival much lower than in the non-Indigenous population, cancer control needs to be a priority of all governments when addressing the gap in Indigenous life expectancy.

Yours sincerely

Anita Tang
Director, Health Strategies Division

The Cancer Council NSW

Submission to the Legislative Assembly
Social Issues Committee

Inquiry into closing the gap: Overcoming Indigenous disadvantage

January 2008

Introduction

The Cancer Council NSW is the leading cancer charity in New South Wales. Our mission is to defeat cancer. The Cancer Council NSW envisages a future where no life is cut short or its quality diminished by cancer. The Cancer Council NSW is currently involved in research and intervention programs relating to tobacco control in Indigenous and disadvantaged communities, and is also running a cancer awareness program for Aboriginal health workers. The Cancer Council NSW welcomes this opportunity to provide comment to the Social Issues Committee of the Legislative Assembly *Inquiry into closing the gap – overcoming Indigenous disadvantage*.

Indigenous people on average die nearly 20 years younger than other Australians. The life expectancy of an Indigenous male is an average of 56 years; for females it is 63 years. This compares with 77 and 82 years for non-Indigenous males and females respectively.[1] Although chronic conditions such as heart disease, stroke and diabetes are known as major contributors of reduced life expectancy in Indigenous people,[1] cancer has been under-recognised by public health authorities as a significant contributor to mortality. Cancer is now the second highest cause of death, after cardiovascular disease, in Indigenous people in NSW. Cancer accounts for 21% of all deaths recorded for Indigenous people in this state[2] (Table 1[*]).

Several issues which influence the high rate of cancer-related deaths in Indigenous people have been brought to the attention of The Cancer Council NSW during research studies and community consultations. These include the high rate of cigarette use, low participation in population-based cancer screening programs and difficulties in accessing transport to medical treatment. The lack of culturally-appropriate general health care, hospital care and palliative care have also been raised.

This submission describes several initiatives to improve the provision of cancer prevention and support services which have been identified as important to the Indigenous community. As cancer is a significant contributor to mortality in Indigenous people, cancer control needs to be a priority of all governments who wish to significantly address the gap in Indigenous life expectancy.

Table 1. Top three causes of death in Indigenous people

Cause of death	NSW	QLD	SA	WA	NT	TOTAL
Cardiovascular disease	156	139	36	97	118	**546**
Malignant neoplasms	106	94	17	53	61	**331**
External injury	65	78	34	60	80	**317**

Source: ABS (2005).

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[*] Data on deaths identified as Indigenous are subject to differing coverage across states and territories; deaths recorded from NSW, Qld, SA, WA and NT only were used in the Australian Bureau of Statistics analysis.

Response to Terms of Reference

Terms of Reference
b). The impact of the following factors on the current lifetime expectancy gap:
ii). Health and wellbeing.

Cancer incidence

NSW has the largest number of people who identify themselves as Aboriginal and Torres Strait Islander of any Australian state or territory. The last census showed that NSW had 29% of the Australia's Indigenous population; an estimated 148,200 people.[3] In NSW, 42% of the Indigenous population resides in a major city, with a third living in inner regional areas, and the remainder in outer regional and remote areas[3] (see Table 2).

Table 2. Place of residence of NSW Indigenous population.

Remoteness Area	Per cent of Indigenous population
Major cities	42%
Inner regional	33%
Outer regional	19%
Remote or very remote	5%

Source: ABS (2006).

However, under-reporting of Indigenous status in health registers, such as the NSW Cancer Registry, means that the true incidence of cancer in this population cannot be established. Studies in the Northern Territory, Queensland, South Australian and Western Australia have found that Indigenous Australians have a different pattern of cancer incidence compared to the general population.

For example, cancer incidence is higher for cancers of the liver, gallbladder, cervix, thyroid, and lung. However, incidence is lower for cancers of the breast, prostate, kidney, bowel, melanoma of the skin and lymphoma.[4] Some of these cancers are smoking-related, and the higher incidence of cervical cancer has been attributed to low uptake of the cervical screening program, however more research needs to be done into the incidence patterns of cancers in the Indigenous population.

Cancer survival and mortality rates

Cancer survival in NSW is now amongst the highest in the world for the non-Indigenous population. Nearly two thirds of people who are diagnosed with cancer will live for five years or longer.[5] The State Government's track record on cancer spending, including the establishment of the Cancer Institute NSW, has directly contributed to these results. Despite this, Indigenous people with cancer are more likely to die from their disease than non-Indigenous people.

A descriptive study of cancer mortality in Indigenous people found that overall the mortality rates from cancer are 1.7 times higher for Indigenous males and 1.6 times higher for Indigenous females when compared with the non-Indigenous population of NSW.[6] Due to the lack of available data on Indigenous status from the NSW Cancer Registry, the study had to use an indirect approach to determine mortality - data from the NSW Cancer Registry was linked with records from the Australian Bureau of Statistics death notification system. Other results from this study included:

- The mortality rate of Indigenous males for oesophageal cancer was more than three times that of the general NSW population. Stomach cancer was more than twice as high for this group.
- For Indigenous females, mortality rates were more than three times that of the NSW population for kidney and cervical cancers.
- Confirming the pattern of previous studies, Indigenous females had 25% lower mortality from breast cancer.
- Mortality from lung cancer was 50% and 100% higher in males and females respectively, compared to the non-Indigenous population.
- Indigenous females also had almost twice the mortality rates for pancreatic cancer. (Both lung and pancreatic cancer are smoking-related cancers).[6]

Mortality from cancer is largely determined by the type of cancer and its prognosis, the stage of disease at diagnosis and access to appropriate treatment. Some of the higher mortality can be attributed to smoking-related cancers (which generally have a poor prognosis) and poor uptake of cancer screening programs (see below). However, better collection of Indigenous status at time of diagnosis and during the course of disease needs to be undertaken in order to facilitate research into causes and patterns of care of cancer treatment in the Indigenous population.

Recommendation 1.
State and federal governments recognise that cancer is a significant cause of morbidity and mortality in Indigenous people. Governments ensure the provision of high quality and culturally-appropriate cancer prevention, detection, treatment care and support services for Indigenous people.

Recommendation 2.
The State Government commits to increasing the proportion of health registry records in which Indigenous status is defined, including those of the NSW Cancer Registry. This would enable greater epidemiological analysis of cancer and other diseases and monitoring of treatment patterns for the Indigenous population.

Tobacco use in Indigenous communities

Cigarette smoking is a major contributor to death and illness in NSW. Smoking contributes to coronary heart disease, a range of cancers, stroke, and chronic lung disease. It is estimated to cause 20% of all cancers and 13% of all cardiovascular disease.[7] In particular, cigarette smoking is responsible for 87% of lung cancer and 70% of chronic obstructive pulmonary disease.[8]

The proportion of the general population who consider themselves current daily smokers has decreased to 17% in recent years.[9] However, there has been little change in cigarette smoking rates for Indigenous people since 1995. The New South Wales Population Health Survey,[10] which conducted a telephone survey of 930 Indigenous adults, found that 43% of Aboriginal adults over the age of 16 years reported that they were daily smokers. This figure may be underestimated, as the rate of telephone ownership is lower-than-average in remote areas. The National Aboriginal and Torres Straight Island Health Survey (NATSIHS), which conducted face-to-face surveys with 10,439 Indigenous Australians in 2004-05, found that half of all adults reported that they were daily users of tobacco.[11]

High smoking rates among very disadvantaged groups means they will have higher rates of morbidity, and premature and preventable death. For example, it is estimated smoking contributes to between one third and two thirds of the difference in male death rates between men in the top socioeconomic and bottom socioeconomic groups.[12] People with severe alcohol and drug dependence are more likely to die from tobacco related causes, such as heart disease, cancer, chronic lung disease and stroke than they are from causes related to the use of any other drugs.[13]

The Cancer Council NSW has commenced the following initiatives regarding tobacco control in Indigenous communities:

1. The Cancer Council NSW is participating in a research project with the Aboriginal Health and Medical Research Council (AH&MRC), the Australian Respiratory Council, and NSW Health among others, which aims to reduce smoking-related disease and morbidity in Aboriginal communities. The project will trial an intervention including the employment of specialist tobacco control workers within Aboriginal Community Controlled Health Services in NSW.

2. The Indigenous community is a target population of The Cancer Council NSW Tobacco and Social Equity Strategy. Part of this strategy includes campaigning for the free provision of nicotine replacement therapy to socially disadvantaged people via agencies which have been trained in appropriate nicotine cessation methods.

Current evidence shows that cessation interventions such as nicotine replacement therapy (NRT) can increase the chances of quitting by one and a half to two times.[14] However, the cost of NRT is frequently cited as a barrier to use for low income and socially disadvantaged groups.[15,16] Currently free NRT is only available to inpatients in NSW public hospitals. Provision of free or heavily subsidised NRT is the most commonly identified strategy by staff of community service agencies to assist their clients to quit smoking.[15]

Both one-to-one counselling and group counselling approximately double the chances of quitting, compared to no treatment. It is also more effective than brief advice alone.[17] Consultation by The Cancer Council NSW suggests there is growing interest and demand for this method of training in the community service sector. Government-funded community services already exhibit many of the characteristics needed to reduce smoking prevalence among their clients, such as a supportive environment, a trusted relationship between clients and staff and the potential to integrate smoking cessation with other life issues.[18] The capacity of the government-funded community services sector can be increased to provide targeted cessation support to their clients.[19] Relevant government-funded community programs whose target groups have high smoking rates include:

- Alcohol and Other Drugs Services
- Mental Health Services

- Brighter Futures
- Families First
- Community Services Grants Program.

Recommendation 3.
Employ a tobacco cessation trainer as a full-time NSW Health position to promote and implement evidence-based smoking cessation training to government-funded community service agencies.

Recommendation 4.
Provide free nicotine replacement therapy to clients of government-funded community service agencies who want to quit smoking. This provision would be administered through the Area Health Services with eligibility limited to those organisations that had participated in appropriate smoking cessation training.

Participation in cancer screening programs

In general, Indigenous people are under-represented in cancer screening and prevention programs.

Only 49% of Indigenous women across Australia have regular pap smear tests within two years; a third less than the general population.[11] The rate of participation in cervical screening programs is lower some areas. A study of Indigenous communities in Queensland found that participation in cervical cancer screening was only 41.5% amongst rural and remote Indigenous women, compared with 59% in the general population.[20] Although the participation rate in cervical cancer screening for the Indigenous women of NSW is not currently reported, mortality from cancer of the cervix is three times higher than that of non-Indigenous women.[6]

Similarly, the number of Indigenous women who reported having regular mammograms to detect early-stage breast cancer has decreased over previous years to 32%.[11] This compares to a screening participation rate in NSW of over 80% in women aged 50 to 69 years.[21]

The recently introduced National Bowel Cancer Screening Program (NBCSP), invited 55 and 65 year olds to undergo a bowel cancer screening test, in order to ultimately remove pre-cancerous polyps or cancerous lesions if necessary. According to the results of the pilot of the national program, the overall response rate was significantly lower for Aboriginal and Torres Strait Islander people than the general population after adjusting for age and sex (actual figures not reported).[22] Mortality rates from bowel cancer are almost 40% higher for the Indigenous population in NSW compared to the non-Indigenous population.[6] More research to uncover the reasons for this is required.

Recommendation 5.

Implement targeted, culturally-appropriate education programs for Indigenous people and health care workers highlighting the importance of cancer screening programs.

Health related transport

Transport to medical treatment is an issue for many cancer patients. The State Government's Community Transport program typically aims to provide one-to-one or group transport to isolated families, the frail aged and people with disabilities in order to facilitate access to a range of services including medical treatment. However, a recent inquiry into community transport commissioned by The Cancer Council NSW estimated that approximately 90,000 people are refused community transport for health-related trips each year in NSW.[23] The study also found that cancer patients are often very ill following treatment and may require specialised transport, which is not available in all areas due to concerns about occupational health and safety from the transport providers.

Although transport is a major issue in rural areas, metropolitan areas also have significant health transport problems. The Cancer Council NSW study found that community transport providers in metropolitan areas refused 1 in 6 requests for health related transport, due to lack of capacity.

Transport for Health/Isolated Patients Travel Accommodation and Assistance Scheme (IPTAAS) is another government subsidy program which provides subsidies to people travelling more than 100km each way to attend an appointment with their nearest medical specialist. IPTAAS is usually used by people who are being transported by private car, or in some instances taking rail or air travel. A federal inquiry into the operation of patient travel schemes such as IPTAAS found that these schemes do not adequately compensate patients and do not overcome distance as a barrier to medical treatment. [24]

Poor transport links have been suggested as one of the causes of the lower survival rates in rural and regional areas.[25,26] Cancer patients from non-metropolitan areas of NSW are 35% more likely to die from their disease than those in major cities.[27] A nation-wide study found that 65% of cancer professionals believed that travel support was a problem for rural and regional patients.[28]

The high up-front costs and low reimbursement rate of health related transport schemes are a barrier to those on lower or fixed incomes. For example, IPTAAS schemes require up-front payment of transport and accommodation costs; only a small proportion of this is generally refunded. The scheme requires a high daily co-contribution from patients, which is often more than the actual cost of travel; this is an added burden for those requiring ongoing medical treatment such as chemotherapy, radiotherapy or dialysis.

As a group, Indigenous people face considerable barriers regarding transport to treatment centres – they have fewer private transport options, are more likely to find cost of travel and accommodation a barrier, or live on geographically isolated settlements.[23] In addition, there have been suggestions that Indigenous communities require more flexible, culturally-appropriate transport options. For example, a greater allowance for carers and family members to accompany a patient, may be more appropriate.

Although many changes are required to improve the access of Indigenous people to government-funded health related transport schemes, The Cancer Council NSW, along with other non-government organisations such as the Council of Social Service of NSW (NCOSS) and the Community Transport Organisation have several initial recommendations, as outlined below.

Recommendation 6.
The following improvements to health transport programs are recommended to improve access to treatment for Indigenous patients and their carers:

IPTAAS

- Eliminate the $20 administration fee for low income clients, including Health Care Card holders, pensioners or people with demonstrable financial difficulty.
- Ensure that people undergoing block or repeated treatments such as radiotherapy need only pay the IPTAAS personal contribution once per treatment cycle.
- Increase the petrol allowance to 21c per kilometre for private vehicles. This would cover the cost of petrol plus minimal wear and tear to the vehicle.
- Introduce measures to remove the need for upfront payments for people on low incomes.
- Review the reimbursement rates for accommodation, especially for the Sydney metropolitan area.
- Adjust the travel and accommodation reimbursement rates on a yearly basis to match consumer price index increases.
- Ensure that reimbursement is provided for the travel and accommodation of carers for Indigenous people where culturally appropriate.
- Allow IPTAAS reimbursement for transport to general medical treatment for people living in isolated areas.

Community Transport

- Increase access to health treatments by expanding funding for non-emergency health transport services by $7 million per year.
- Ensure that appropriate community transport services are available in all areas for those with special requirements such as cancer patients.
- Create health transport options for Aboriginal people, by providing dedicated and culturally-appropriate services to Aboriginal communities, including increasing the network of Aboriginal transport coordinators.

Indigenous palliative care issues

Palliative care is any form of treatment that concentrates on reducing the severity of the symptoms of a disease or slowing its progress, rather than providing a cure. Palliative care aims to improve the quality of life of patients, their families and carers by addressing the problems associated with terminal illness.[29]

Although palliative care would not necessarily lengthen the life of an Indigenous person with a terminal illness, not having access to appropriate services may mean that people are unable to die in accordance with their cultural and spiritual beliefs, or may experience unnecessary pain at the end-of-life.

There are limited studies in Indigenous palliative care, however anecdotal evidence suggests that Indigenous people and other culturally diverse groups do not access palliative care services when needed. For example, The Cancer Council NSW held an Indigenous forum in Darwin, which heard that many Indigenous people would like culturally-appropriate places for people to visit or stay whilst their relative is in a hospital or hospice.

Further research is needed into the needs of Indigenous people regarding access to culturally-appropriate palliative care, although there is some reported evidence that Aboriginal people have special palliative care needs related to their cultural beliefs and social situation.[30] The Palliative Care Association noted that, because of past experiences, many Indigenous people mistrust government services including health care services. This would necessarily impact on their willingness to access general as well as palliative care.[30]

In addition, the Department of Health and Ageing (DoHA) commissioned a study into the provision of palliative care services to Indigenous Australians.[31] The study found that, in most regions, Indigenous clients are either not referred to palliative care services or are referred at a very late stage of their illness. Being able to be treated at home whilst ill was the preferred option of most respondents to the study. The study also found that in both metropolitan and rural areas, palliative care services are generally provided by mainstream service providers which often do not have formal networks with Indigenous health services.

Recommendation 7.

Ensure that culturally-appropriate palliative care services are available at home, hospitals, and hospices for Indigenous people, including appropriate visiting and meeting places for their relatives, friends and carers where necessary.

Ensure ongoing professional development initiatives for primary health professionals and palliative care specialists in effective, culturally-appropriate communication and education techniques.

Conclusions

Cancer is one of the main causes of death in the Australian Indigenous population. Compared to the non-Indigenous population, cancer has a different incidence pattern and worse survival rates in Indigenous people. Many of these cancers are preventable through behaviour change or screening programs, or have better outcomes with optimal medical care. Thus a government commitment to increasing the life expectancy of Indigenous people must include targeted and culturally-appropriate cancer control initiatives.

Although many changes are required at all levels of health services and within communities to reduce the gap in life expectancy between Indigenous Australians and the general population, The Cancer Council NSW has highlighted several issues in this submission which were raised during community consultations and research studies:

- Overall, data regarding the epidemiology of cancer in Indigenous population is lacking.
- Increasing the quality of notifiable data regarding Indigenous status will enable the targeting and monitoring of specific cancer control initiatives.
- Targeted tobacco campaigns and initiatives including the provision of free nicotine replacement therapy to those who are most disadvantaged will assist in reducing the smoking rate.
- Specific campaigns aimed at increasing the participation of Indigenous people in cancer screening programs will decrease morbidity and mortality related to breast, cervix and bowel cancers.
- Affordable and culturally-appropriate access to non-emergency health transport underpins many of the issues relating to general health maintenance as well as cancer control.
- Culturally-appropriate medical care is needed, including for those Indigenous people with a terminal illness who require end-of-life care.

The implications of improving cancer prevention, medical treatment and palliative services for Indigenous people will significantly contribute to improving the health status of all Indigenous people in NSW and therefore will help to ‘close the gap’ in life expectancy between Indigenous and non-Indigenous peoples or contribute to improved quality of life.

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Summary list of The Cancer Council NSW recommendations

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Recommendation 7.

Ensure that culturally-appropriate palliative care services are available at home, hospitals, and hospices for Indigenous people, including appropriate visiting and meeting places for their relatives, friends and carers where necessary.

Ensure ongoing professional development initiatives for primary health professionals and palliative care specialists in effective, culturally-appropriate communication and education techniques.