

# Cancer, Health Services and Indigenous Australians

John Condon, Cooperative Research Centre for Aboriginal and Tropical Health



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In 2003, a series of papers was commissioned to provide information, analysis and advice to Government as part of a Review of the Australian Government's Aboriginal and Torres Strait Islander Primary Health Care Program. The Review examined issues relating to funding for comprehensive primary health care for Aboriginal and Torres Strait Islander people and the impact of activity in this area. The commissioned material complemented information obtained from previous reviews and evaluations as well as that obtained from program data.

An Interdepartmental Committee (IDC) oversaw the Review process. Members of the IDC were from the Australian Government Departments of the Treasury; Prime Minister and Cabinet; Finance and Administration; Immigration and Multicultural and Indigenous Affairs; Health and Ageing (Chair); and Aboriginal and Torres Strait Islander Services.

This is Volume 5 of the published Review papers.

The papers in this series are:

*Volume 1. National Strategies for Improving Indigenous Health and Health Care* by Judith Dwyer, Kate Silburn and Gai Wilson, La Trobe University.

*Volume 2. Investment Analysis of the Aboriginal and Torres Strait Islander Primary Health Care Program in the Northern Territory* by Carol Beaver, Centre for Chronic Disease, University of Queensland and Yuejen Zhao, Health Gains Planning Unit, Department of Health and Community Services, Northern Territory.

*Volume 3. Costings Models for Aboriginal and Torres Strait Islander Health Services* by Econtech Pty Ltd.

*Volume 4. Capacity Development in Aboriginal and Torres Strait Islander Health Service Delivery – Case Studies* by Cindy Shannon and Helen Longbottom, School of Population Health, University of Queensland.

*Volume 5. Cancer, Health Services & Indigenous Australians* by John Condon, Cooperative Research Centre for Aboriginal and Tropical Health.

*Volume 6. Maternal and Child Health Care Services: Actions in the Primary Health Care Setting to Improve the Health of Aboriginal and Torres Strait Islander Women of Childbearing Age, Infants and Young Children* by Sandra Eades, Menzies School of Health Research.

*Volume 7. Substance Misuse and Primary Health Care among Indigenous Australians* by Dennis Gray, National Drug Research Institute, Curtin University of Technology; Sherry Saggars, Centre for Social Research, Edith Cowan University; David Atkinson, Rural Clinical School, University of Western Australia and Phillipa Stempel, National Drug Research Institute, Curtin University of Technology.

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## Cancer, Health Services and Indigenous Australians

Indigenous Australians have much more severe health problems than other Australians. The causes can be traced back through immediate behavioural risk factors (obesity, smoking, etc.) to social, educational, environmental and economic factors, and on to cultural and historical factors such as dispossession, loss of individual and community control and breakdown of community structures based on respect and authority. While the health system cannot deal directly with all of these issues, it can reduce excessive disease occurrence through primary and secondary prevention, and reduce the impact of injury and disease through clinical care. One of the greatest challenges facing Australia's health system is to prevent the occurrence and progression of disease and reduce suffering for Indigenous Australians as effectively as it does for Australians generally.

While cancer is not the highest priority Indigenous health issue, it does have a greater impact on Indigenous Australians than other Australians and can provide a more complete picture of disease occurrence and health system response than is possible for many other Indigenous health problems. This paper explores the performance of the Australian health system in relation to cancer control for Indigenous Australians in the Northern Territory (NT). It compares cancer mortality, incidence and survival for the Indigenous population of the NT with that of the total Australian population. It also describes the prevalence of cancer risk factors and screening behaviour, within the limits of available data. Differences between Indigenous Australians and other Australians in these areas point to deficiencies in the response of the Australian health system in preventing, detecting and treating cancer in Indigenous Australians.

### Cancer and health system performance

All components of the health system have a role in reducing the impact of cancer, from health promotion and environmental health programs reducing cancer risk factors, to palliative care alleviating suffering when cure is not possible. The health system can reduce the impact of cancer through:

- reduction in risk factors;
- screening detection of pre-malignant changes and early cancers;
- early investigation and diagnosis;
- coordinated and specialised treatment; and, for some
- palliative care.

Effective action is often a collaborative effort between different parts of the health system, or between the health system and other service sectors.

Other than the very common sun-related skin cancers, cancer affects most people only once during their life; cancer diagnosis, treatment and outcome (cure or death from the disease) are important and intensive events. These features of cancer provide an opportunity to monitor disease occurrence and health system performance that is not available for most other health problems. Because cancer is a relatively uncommon and serious disease:

- its diagnosis can be accurately identified;
- there is a standardised system for classifying disease progression at time of diagnosis (the staging system), curative treatment is intense and discrete (principally surgery, radiotherapy and chemotherapy); and
- data for treatment outcomes (survival rates) are readily available.

In Australia population-based cancer registries collect data and publish regular reports on cancer incidence (occurrence), mortality and survival rates. Clinical cancer registries in specialist cancer treatment centres monitor diagnosis, treatment, complications and outcome. National cancer control programs such as BreastScreen Australia and the Cervical Cytology Registers that operate in all states and territories provide information on cancer prevention and early detection programs. These data sources form the basis for much research into the causes, prevention and treatment of cancer.

Until recently, cancer has not been seen as a health priority for Indigenous Australians<sup>(1;2)</sup>. However, cancer is one of the leading causes of death for both Indigenous and non-Indigenous people, causing 16% and 29% of deaths respectively in 2001<sup>(3)</sup>. Several preventable cancers occur more commonly in Indigenous than other Australians and cancer survival for most cancers is lower for Indigenous than other Australians, indicating that preventive strategies and clinical care are not as effective as they could, and should, be for Indigenous Australians<sup>(4)</sup>. Information on cancer is not as comprehensive for Indigenous Australians as for the general Australian population, but the information that is available provides a better evidence base to explore cancer occurrence and health system performance than is available for other Indigenous health issues.

Exploring the experience of Indigenous people and their outcomes in relation to cancer incidence, stage of disease at presentation, access to treatment, survival and mortality can help illustrate aspects of Indigenous Australians' access to and interaction with the health system. This provides an opportunity to monitor health system performance for Indigenous Australians on a population-wide basis with a ready comparison to the non-Indigenous population. Monitoring health system performance in cancer care for Indigenous Australians is feasible and important in itself. More significantly, monitoring cancer care may be an indicator of overall health system performance and affords an opportunity to monitor both primary care and specialist services, and the interaction between them.

## Data availability

Despite the very comprehensive Australian cancer surveillance system described above, no national information is available for Indigenous people on cancer mortality, incidence and survival and cancer health services such as screening programs. The most comprehensive and detailed data are for Indigenous people in the NT, with limited data available for South Australia and Western Australia. Data from the eastern States is available only for isolated cancer issues, predominantly from individual research projects.

The impact of cancer on Indigenous Australians and the performance of the health system in providing cancer services will be illustrated predominantly with data from the NT, supplemented where possible by data from other States to confirm similarities or point out differences. Most comparisons are made to the total Australian population rather than the NT non-Indigenous population because large random fluctuations can occur in cancer statistics in the small NT non-Indigenous population and because very high levels of smoking and alcohol consumption make the NT non-Indigenous population unrepresentative of the total Australian non-Indigenous population with respect to cancer.

The experience of the NT Indigenous population may not be exactly representative of Indigenous people throughout Australia. The NT Indigenous population comprises approximately 13% of the total Australian Indigenous population. Compared to the total Indigenous population, the NT Indigenous population has a similar median age but a higher proportion of people living in rural and remote areas, a higher level of overcrowded homes, and lower median income and level of completed education<sup>(5)</sup>. The NT Indigenous population has a shorter history of contact with non-Indigenous society than for most other Indigenous Australians, particularly those in eastern States. However, available evidence from other States, including from the eastern States, indicates that cancer has a similar impact on Indigenous people elsewhere as it does

on Indigenous people in the NT, and that differences in the impact of cancer between Indigenous people in each State are small in comparison to the differences between Indigenous and other Australians<sup>(4)</sup>.

## Cancer mortality

Cancer mortality rates are higher for Indigenous Australians than other Australians. In the NT in 1991–2000 the Indigenous mortality rate for people aged under 65 years was more than double the total Australian rate (rate ratio & 95%CI: 2.2, 2.0-2.5). However, for people aged 65 and over Indigenous mortality was the same as the total Australian rate (1.0, 0.9-1.3)<sup>(6)</sup>. Higher Indigenous cancer mortality rates have also been reported for Western Australia (WA) and South Australia (SA)<sup>(7,8)</sup>.

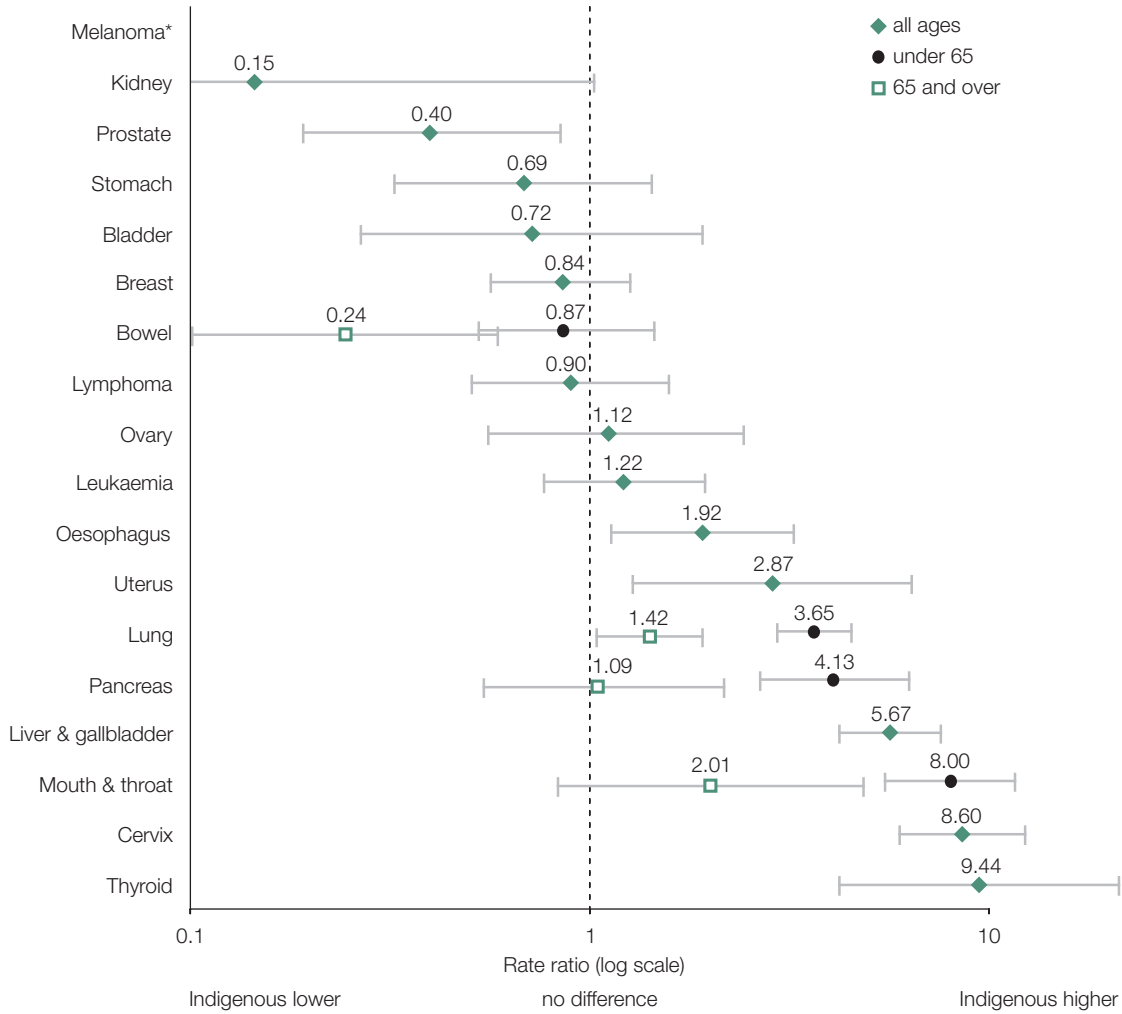
Indigenous Australians have a different pattern of cancer mortality at specific cancer sites compared with the total Australian population. Compared with total Australian rates, NT Indigenous people have lower mortality rates for cancer of the prostate and melanoma of skin, but higher rates for cancer of the oesophagus, uterus, lung, pancreas, liver, mouth and throat, cervix and thyroid (cancers with higher or lower rates are those for which the confidence interval of the rate ratio does not include 1.0) (Figure 1). Mortality from cancer of the cervix and thyroid is more than nine times higher for NT Indigenous people than the total Australian population. A similar pattern of cancer mortality (relative to non-Indigenous rates) has been reported for Indigenous people in WA and SA<sup>(7)</sup>.

In the NT, mortality from several cancers was higher (relative to total Australian rates) for younger (aged 0–64) than older (aged 65+) Indigenous people (Figure 1). For bowel cancer in younger people, Indigenous mortality was similar to total Australian rates but in older people Indigenous mortality was 75% lower. NT Indigenous mortality from cancer of the lung, pancreas and mouth and throat in young people was several times higher than total Australian rates but in older people was similar to or only slightly higher than total Australian rates. These latter three cancer sites are all smoking-related cancers.

## Trends in cancer mortality

The NT Indigenous mortality rate for smoking-related cancers almost doubled between 1977 and 2000 (Figure 2). Lung cancer mortality more than doubled in this period to be twice as high as the total Australian rate; over the same period Australian male lung cancer mortality fell by 25% while Australian female mortality stopped rising<sup>(9)</sup>. Indigenous cervical cancer mortality in the NT was many times higher than the total Australian rate from 1977 to 1996, but dropped by 50% in 1997 to 2000 (Figure 3). In contrast, NT Indigenous breast cancer mortality was much lower than the total Australian rate until 1996, but was slightly higher than the total Australian rate in 1997 to 2000 (Figure 3). These changes may be only random fluctuations in the number of deaths in a small population in a short time-period, or they may be the first indications of long-term changes in mortality for these two cancers. There have been no reports from other States of long-term trends in Indigenous cancer mortality.

Figure 1: Cancer mortality rate ratio<sup>a</sup>, NT Indigenous: total Australia, 1991–2000<sup>b</sup>



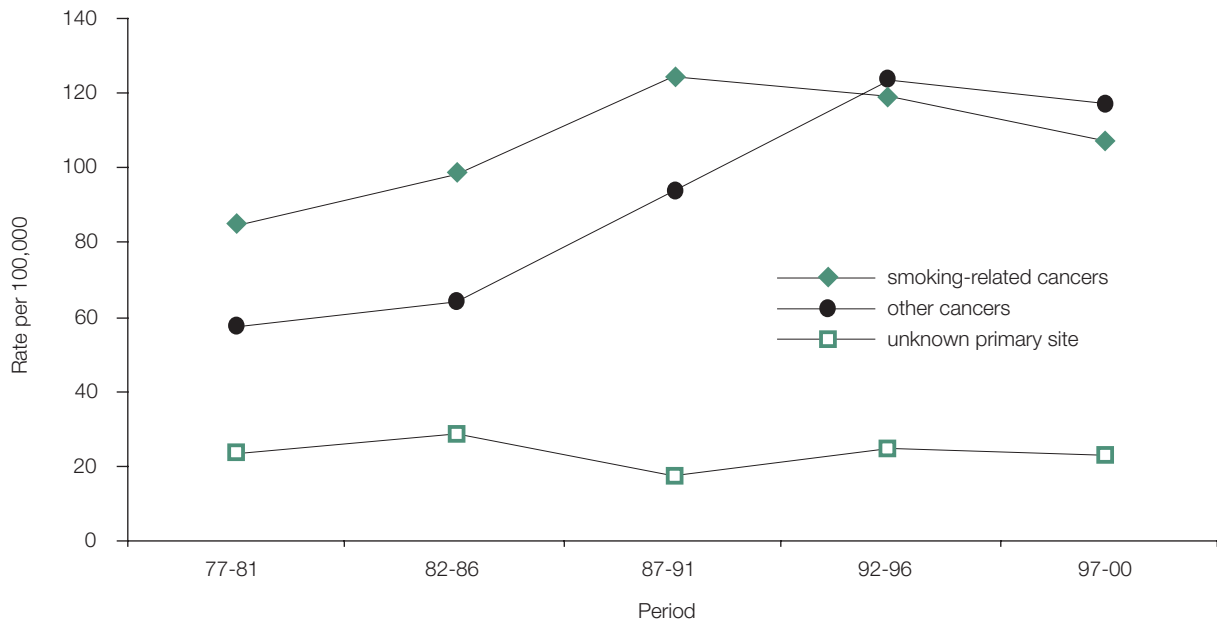
a. Ratio for all ages combined (adjusted for age and sex), except for cancer sites where there was a statistically significant difference between the ratio for people aged 0–64 years and those aged 65+ years, for which the ratio for both age-groups is shown separately.

b. Cancer sites are ranked in order of rate ratio for all ages combined or age-group 0-64 years.

\* There were no NT Indigenous deaths due to melanoma in this period (i.e. rate ratio = 0)

Source: <sup>(9)</sup>

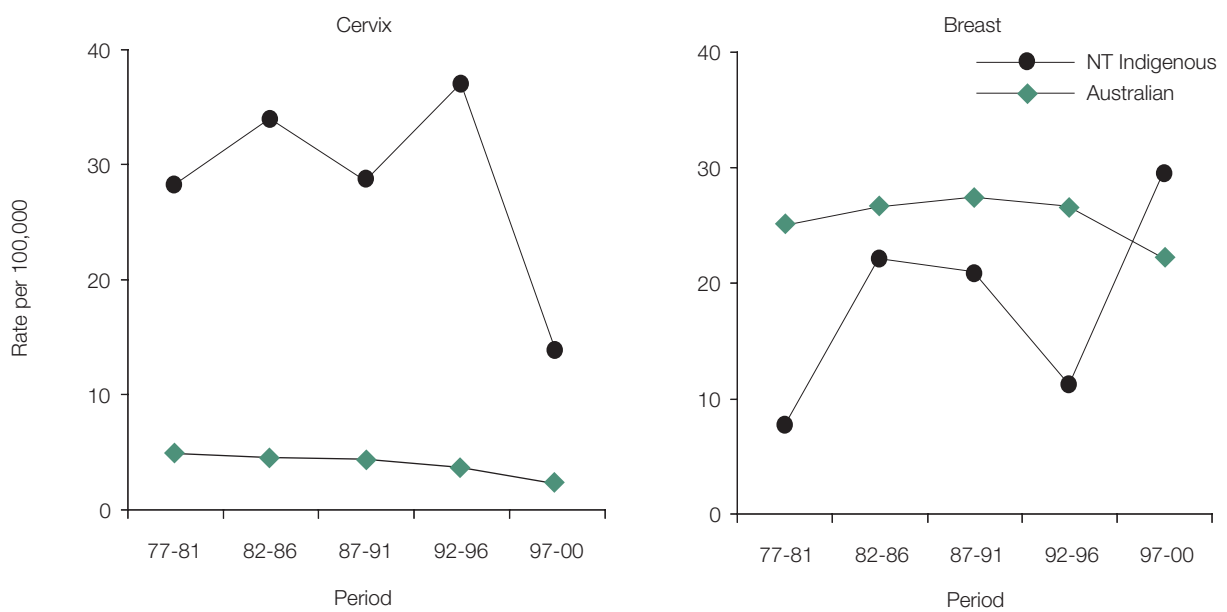
Figure 2: Trends in NT Indigenous age-standardised mortality rate for smoking-related cancers<sup>a</sup>, 1977–2000



a. Cancers of the mouth and throat, oesophagus, stomach, anus, pancreas, larynx, lung, vulva, penis, bladder and kidney (parenchyma and pelvis).

Source: <sup>(9)</sup>

Figure 3: Trends in NT Indigenous age-standardised mortality rate for cancer of the breast and cervix, 1977–2000



Source: <sup>(9)</sup>

Cancer mortality is higher for Indigenous Australians than other Australians for many cancer sites. Higher mortality could be due to higher incidence of some cancers (i.e. these cancers are more common in Indigenous people than other Australians) or to lower survival for Indigenous people who have cancer (i.e. fewer Indigenous people are cured of these cancers), or to a combination of these two factors. For some cancers, higher incidence is part of the explanation, but lower survival is also a major factor. For other cancers, Indigenous incidence rates are similar to or lower than total Australian rates—higher mortality is due entirely to lower survival.

## Cancer incidence

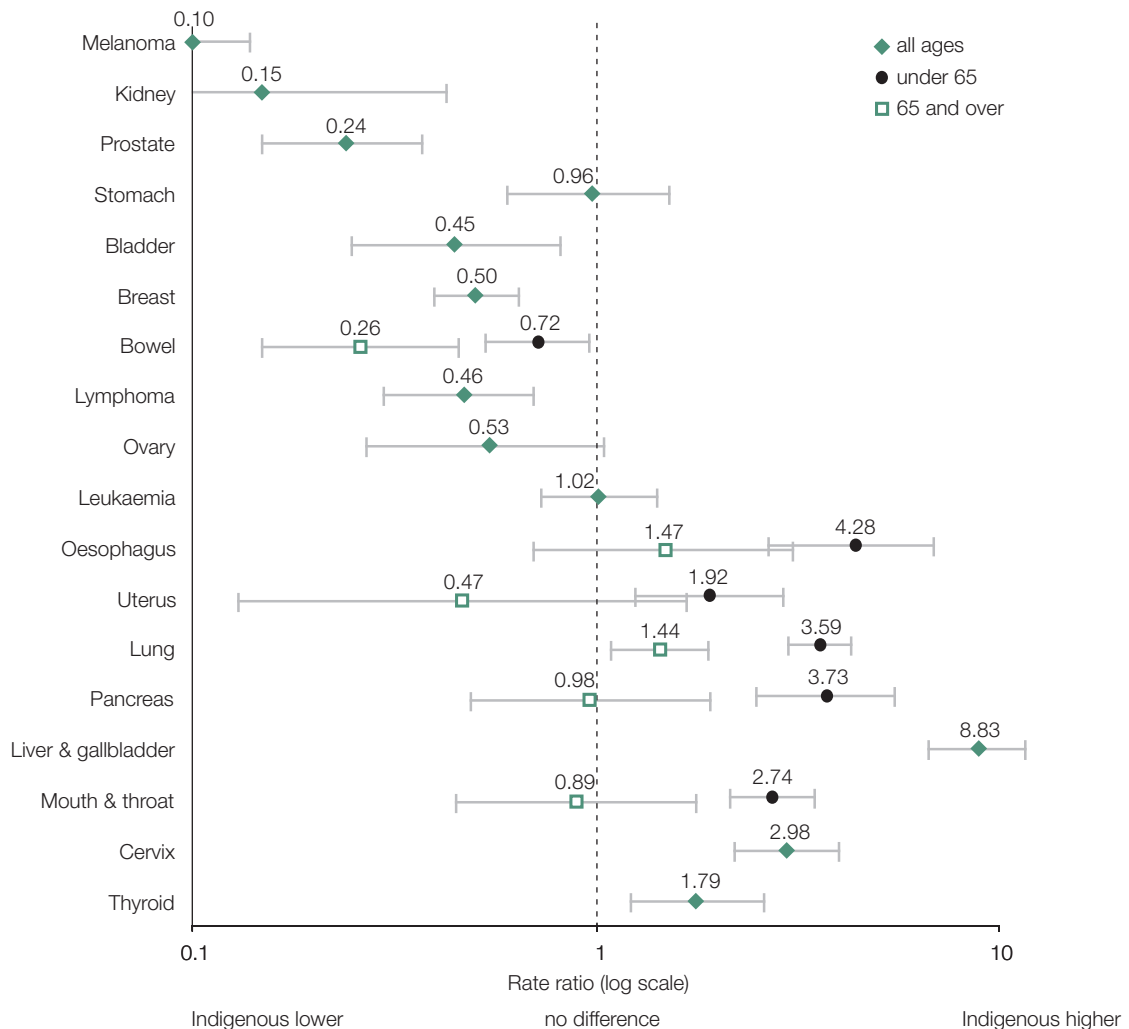
Indigenous Australians have a different pattern of cancer incidence at specific cancer sites than the total Australian population. Compared with total Australian incidence rates, Indigenous cancer incidence in the NT is higher for cancer of the liver and gallbladder, cervix, thyroid and lung, but lower for cancer of the breast, prostate, bladder, kidney, bowel, melanoma of skin and lymphoma (Figure 4). A similar pattern of cancer incidence has been reported for Indigenous people in SA, WA and thirteen Indigenous communities in Queensland<sup>(10-12)</sup>.

For several smoking-related cancers, NT Indigenous incidence rates are not higher than total Australian rates in older people (aged 65+), but are considerably higher in younger people (aged 0–64) (Figure 4). For younger people, NT Indigenous incidence rates for cancers of the mouth and throat, oesophagus and pancreas are three to four times higher than total Australian rates but for older people are similar to total Australian rates. Lung cancer incidence is higher in NT Indigenous people at all ages, but much higher in younger people than older people. For bowel cancer, NT Indigenous rates are lower than total Australian rates for all age groups, but much lower for older than younger people.

### Trends in cancer incidence

No reports have been published of time-trends in Indigenous cancer incidence. Analysis of unpublished data from the NT Cancer Registry for the years 1991–2001 indicate that the incidence of several smoking-related cancers (mouth and throat, oesophagus and pancreas) increased over that period, but the increase was statistically significant only for cancer of the pancreas. Lung cancer incidence did not increase. Breast cancer incidence also increased considerably during that period (and the increase was statistically significant); this increase was from very low levels in the early 1990s and the incidence rate at the end of the period was still more than 30% lower than the total Australian rate<sup>(13)</sup>.

Figure 4: Cancer incidence rate ratio<sup>a</sup>, NT Indigenous:total Australia, 1991-2001<sup>b</sup>



a. ratio for all ages combined (adjusted for age and sex), except for cancer sites where there was a statistically significant difference between the ratio for people aged 0-64 years and those aged 65+ years for which the ratio for both age-group is shown separately.

b. cancer sites are ranked in the same order as for mortality in Figure 1.

Source: <sup>(13)</sup>

## Cancer survival

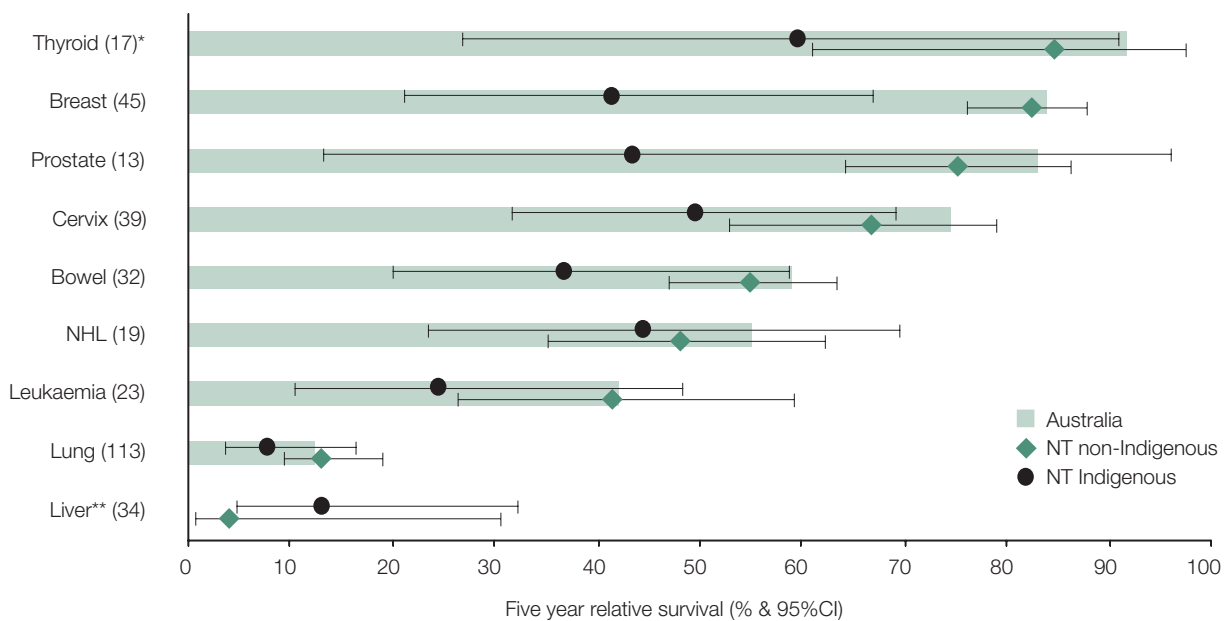
The five-year cancer survival rate is the proportion of people with cancer who are still alive five years after their cancer was diagnosed, and is often used as an approximate indicator of disease cure rates. There are very large differences in cancer survival between Indigenous Australians and other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

Lower survival for all cancers combined has been reported for Indigenous people in SA; survival for specific cancer sites was not reported<sup>(10)</sup>. The only information available for Indigenous survival for specific cancer

sites are preliminary results from analysis of NT Cancer Registry data for NT Indigenous people diagnosed between 1991 and 1999 (Figure 5). Indigenous cancer five-year relative survival rates were lower for almost all of the most common cancer sites. Although the number of cases in Indigenous people at each specific cancer site is small and confidence intervals for Indigenous survival rates are consequently wide, the differences were statistically significant for cancer of the thyroid, breast, cervix and bowel, and the differences were large and close to statistical significance for cancer of the prostate and leukaemia. The NT non-Indigenous survival rate was similar to the total Australian rate for all cancer sites examined, indicating that effective cancer treatment is available; lower Indigenous survival was not due to absence of cancer treatment services in the NT.

The absolute difference in cancer survival is greatest for cancers with the highest survival in non-Indigenous people—cancers of the thyroid, breast, prostate and bowel. For cancer of the thyroid, five-year survival for all Australian cases is over 90% and for breast cancer over 80%, compared with only 60% and 42% respectively for NT Indigenous cases. These cancers are 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 Indigenous people with these cancers.

Figure 5: Cancer survival, NT Indigenous and NT non-Indigenous<sup>(a)</sup> and total Australia<sup>(b)</sup>



\* Number of Indigenous cases.

\*\* Three-year relative survival rate for primary liver cancer.

(a) NT data: cases diagnosed 1991–1999.

(b) Australian data: cases diagnosed 1992–1997. Australian liver cancer survival rate not available.

Source: <sup>(6, 14)</sup>

## Relationship between cancer mortality, incidence and survival

For cancer of the lung, liver and pancreas, higher cancer mortality in Indigenous Australians is almost entirely due to higher cancer incidence. Incidence rate ratios (comparing NT Indigenous to total Australian rates) are similar to mortality rate ratios and there are only small differences between Indigenous people and other Australians in cancer survival. These cancers are those for which survival rates for non-Indigenous people are very low; Indigenous cancer survival could not be much lower.

For other cancers, higher Indigenous mortality is due to a combination of higher incidence and lower survival. Cancers of the thyroid and cervix have higher incidence and lower survival for Indigenous than non-Indigenous people. Even for cancers that have lower incidence in Indigenous people such as breast cancer (incidence rate ratio of 0.50), Indigenous mortality rates are relatively higher (mortality rate ratio of 0.84) because survival is only half that of the total Australian rate (42% compared with 82%). Cancers of the breast and bowel are two of the few health issues for which Indigenous people have lower incidence than other Australians, but this advantage is eliminated by less effective health care and lower chance of cure.

## Cancer risk factors

The cancers that have higher incidence in Indigenous people are almost all preventable, particularly through reduced tobacco consumption, increased Pap test coverage and follow-up treatment, Hepatitis B immunisation, and reduced alcohol misuse.

### Lung and other cancer risk factors: Tobacco consumption

Curative treatment is not usually possible for lung cancer and five-year survival is very low (approximately 15% for Australians generally). Prevention through reduction in tobacco consumption is far and away the highest priority to reduce the impact of lung and other smoking-related cancers on Indigenous Australians.

For several smoking-related cancers including lung cancer, NT Indigenous mortality and incidence rates were much higher (relative to total Australian rates) in younger than older people (Figure 1, Figure 4). As noted above, no information is available on long-term trends in Indigenous cancer incidence. However, since survival from cancer of the lung and pancreas is very low, the large increase in Indigenous mortality from these smoking-related cancers (Figure 2) indirectly indicates increasing incidence of these cancers since 1977. The increasing mortality from smoking-related cancers and the relatively greater incidence and mortality in younger Indigenous people indicate that smoking has had a greater impact on younger Indigenous people than older Indigenous people in the NT, and that this impact is increasing, possibly reflecting an increase in tobacco consumption by Indigenous people in recent decades.

Nationally, approximately 50% of Indigenous adults smoke tobacco, double the proportion of the total Australian population<sup>(15)</sup>. There is some regional variation, with over 70% of adults smoking in coastal communities of the NT but low smoking levels in Central Australia where a high proportion of Indigenous people, particularly women, chew tobacco rather than smoke it<sup>(16)</sup>. Indigenous people appear to have different perceptions of smoking risks to other Australians. In response to a survey question on which of several listed substances caused the most deaths, less than 5% of Indigenous Australians in urban areas chose tobacco compared with over 30% of other Australians. Over 60% of Indigenous Australians named alcohol as causing the most deaths, and more named petrol sniffing, cocaine and heroin than tobacco<sup>(17)</sup>.

Smoking reduction programs for Indigenous communities are not as well established or coordinated as in the general Australian population and few have been evaluated<sup>(18)</sup>. No evidence is available on trends in Indigenous smoking prevalence.

### Liver cancer risk factors: Alcohol consumption and Hepatitis B carriage

As for lung cancer, prevention is the only effective strategy to deal with primary liver cancer—treatment is rarely curative and survival rates are very low. The major risk factor for primary liver cancer in Indigenous people is chronic infection with the Hepatitis B virus<sup>(19)</sup>. Hepatitis B infection is acquired in childhood by a high proportion of Indigenous people; in early childhood it causes only mild or no clinical illness and the virus is eliminated without long-term damage. However, in a proportion of infected children the infection persists indefinitely and after several decades may cause chronic liver damage or primary liver cancer. Evidence from NT remote communities between 1971 and 1990 indicates that approximately 13% of Indigenous adults had chronic Hepatitis B infection<sup>(19)</sup>. In the late 1980s, 14% of Indigenous children less than 17 years of age in a small New South Wales town were found to have chronic Hepatitis B infection<sup>(20)</sup>.

Vaccination against Hepatitis B in infancy prevents infection and thus prevents primary liver cancer in later life. Hepatitis B vaccination commenced for Indigenous children in 1987, and for all Australian children in 2000. The Australian Childhood Immunisation Register reported that in March 2003 Hepatitis B vaccination was up-to-date for 95% of Australian children aged 12–15 months<sup>(21)</sup>. Coverage rates are not available for Indigenous children, but coverage in the NT, where over a third of children are Indigenous, was 97%. Immunisation programs delivered by primary health care services, if maintained at these high levels, will lead directly to a reduction of primary liver cancer incidence in the next two to three decades.

Alcohol misuse also plays a part in causing primary liver cancer, although the risk from excessive alcohol consumption is not as high as that from chronic Hepatitis B infection. A smaller proportion of Indigenous Australians report being consumers of alcohol than do other Australians, but of those who do consume alcohol a very high proportion consume at dangerous levels. In surveys conducted in 1993 and 1994, 33% of urban Indigenous adults reported being current drinkers compared with 45% in the general population, but of Indigenous people who reported drinking at least weekly, 79% consumed alcohol at harmful levels, compared with only 12% in the general population<sup>(17)</sup>.

As in the rest of the community, reduction of alcohol misuse by Indigenous people requires a multi-sectoral approach, in which primary health care services are involved through individual client services (brief interventions, referral to specialist rehabilitation services, etc.), through conduct of community programs and through lobbying for social, political and policy changes such as taxation changes to decrease demand for full strength alcohol products and licensing restrictions to reduce alcohol availability.

### Pap tests and cervical cancer

Cervical cancer incidence can be reduced by achieving a high coverage of regular Pap tests and, in collaboration with specialist gynaecology services, follow-up of abnormal Pap tests to prevent progression to invasive cancer. Pap test coverage for Indigenous women is lower than the total Australian coverage rate, but there are indications that Indigenous coverage is increasing.

Pap test coverage for Indigenous women has been reported from individual health services or communities to be low, with reports that 27% to 63% of women have ever had a Pap test and one report that 37% of women had had a Pap test within the previous three years<sup>(22-24)</sup>, compared with a national coverage (excluding Queensland) reported for 1996/1997 of 62% of women aged 20–69 years having had a Pap test in the preceding two years<sup>(25)</sup>.

Pap test coverage statistics are not available from State and Territory Pap Test Registers for Indigenous women separately, but coverage rates for all women combined in areas with predominantly Indigenous populations can indirectly indicate Pap test coverage for Indigenous women. For 13 predominantly Indigenous communities in Queensland, 41% of all women had a Pap test recorded by the Queensland Pap Smear Registry in the two-year period to February 2001, compared to 59% for the total Queensland population; participation for individual communities ranged from 20% to 64%<sup>(26)</sup>. A recent study in New South Wales compared regional variations in Pap test coverage (for the total regional population) with the proportion of Indigenous people in each region. Areas with a high proportion of Indigenous people had lower Pap test coverage than areas with a lower proportion of Indigenous people. However, this variation was associated with rural and remote areas, not with the proportion of Indigenous people in the population, indicating that Indigenous women have lower Pap test coverage than other New South Wales women because more of them live in remote areas rather than directly because they are Indigenous<sup>(27)</sup>.

The evaluation of the NT Well Women's Program reported Pap test coverage rates for the two-year period April 1997 to March 1999 for five NT districts with predominantly Indigenous populations<sup>(28)</sup>. Pap test coverage was highest in the Alice Springs Rural district (61%) and lowest in the Barkly district (36%) (Table 1). Pap test coverage in the Katherine district increased from 48% in 1990–92 to 56% in 1997–99; no other district had comparable data for Pap test coverage in previous years<sup>(29)</sup>. Pap test coverage was later reported to have increased by several percent between July 1998 and April 2001 for four of these five districts<sup>(30)</sup>. The NT-wide Well Women's Program commenced in 1994. Alice Springs Remote district, which had the highest Pap test coverage and the lowest proportion of non-Indigenous women, had a local Well Women's Program from 1988, initiated and coordinated by community-controlled Aboriginal Health Services after lobbying by Aboriginal women. Protocols for women's health screening were first published by Congress Alukura and Nganampa Health Council in 1990<sup>(28)</sup>. The high Pap test coverage in this district, comparable to the national coverage rate, is very likely due to the long-sustained local commitment to Pap test screening as part of the Well Women's Program.

The lower NT Indigenous cervical cancer mortality rate in 1997–2000 than in previous years (Figure 3) may be the first indication of Pap test programs reducing cancer mortality, but may also be random fluctuation due to small numbers. There was not a corresponding fall in cervical cancer incidence in the same period.

Research in Queensland found many barriers for Indigenous women to participation in Pap test screening including:

- lack of knowledge about cervical cancer and awareness of Pap test screening;
- communication difficulties between mainstream health services and Indigenous women;
- ineffective screening promotional strategies and information materials;
- a forbidding atmosphere at mainstream health services including lack of Indigenous staff;
- hostile non-Indigenous staff and lack of privacy;
- a mental association of cervical screening with treatment for sexually transmissible infections; and
- lack of female doctors<sup>(31)</sup>.

The NT Well Women's Program was recommended as a service delivery model that overcame many of these barriers. The evaluation of the Well Women's Program confirmed the success of this model<sup>(28)</sup>.

**Table 1: Pap test coverage (women aged 20–69 years), NT remote districts, April 1997 to March 1999.**

District	Female population		Pap test coverage (%)		
	Number <sup>a</sup>	Indig. (%) <sup>b</sup>	District	Town <sup>c</sup>	Remote <sup>c</sup>
Alice Springs Remote	3207	75	61	na	61
Barkly	1855	53	36	55	23
Darwin Rural	3134	71	43	na	43
East Arnhem	3635	49	49	83	38
Katherine	4702	42	56	~56	~56

a. Number of women aged 20–69 in each district.

b. Proportion of women who are Indigenous.

c. Pap test coverage for women living in the district service centres (the towns of Tennant Creek, Nhulunbuy and Katherine) and for women living outside these towns. District service centres are not included in the Alice Springs Remote and Darwin Rural districts.

## Cancers with lower incidence in Indigenous people

The lower incidence of breast cancer can be partially explained by the early age of first childbirth, high number of pregnancies and possibly longer duration of breastfeeding for Indigenous women, all of which are protective factors for breast cancer. The high level of melanin pigmentation in the skin of Indigenous people explains their lower incidence of melanoma of the skin. However, reasons for the lower incidence rates of other cancers such as bowel, kidney and bladder are not apparent.

## Cancer diagnosis and treatment

### Diagnosis

The first aspect of cancer treatment that may be a contributor to lower Indigenous cancer survival is late diagnosis. Cancer that has spread from the site of origin in the body is harder to treat and less likely to be cured than localised disease. If Indigenous people have more advanced disease when they are diagnosed they also have a lower chance of successful treatment. The extent to which cancer has spread from the original site is termed the 'stage at diagnosis' of the cancer, and classified as:

- local disease only;
- direct invasion to surrounding tissues; and
- distant spread.

The only published report of cancer stage at diagnosis for Indigenous people is for 139 cases diagnosed with cancer in SA in 1988–1994<sup>(10)</sup>. Indigenous people with cancer were more likely to be diagnosed with disease that had spread beyond the tissue of origin than non-Indigenous people (50% compared with 40%). Results were not reported for specific cancer sites. Preliminary results from current research in the NT confirm this finding, although it was not consistent for all cancer sites; a higher proportion of Indigenous Australians than non-Indigenous people were diagnosed with more advanced disease for cancer of the bowel, breast, cervix and lymphoma, but not for cancer of the lung<sup>(32)</sup>.

The SA study calculated five-year survival rates for Indigenous people after adjusting for the difference in stage at diagnosis. The difference between Indigenous and non-Indigenous Australians' survival before adjustment (37% compared with 49%) was reduced by only one-third after adjustment (40% compared with 48%), indicating that late diagnosis was only part of the explanation for lower Indigenous survival rates; other, as yet unidentified, factors are also involved<sup>(10)</sup>. Other factors 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 Indigenous people less likely to survive major surgery and the complications of chemotherapy and radiotherapy.

## Treatment

There have been several reports that hospital admission rates for cancer were lower for Indigenous than non-Indigenous people in the 1980s and early 1990s, but these reports did not take into account the different pattern of incidence at specific cancer sites in Indigenous people<sup>(33-35)</sup>. No reports of treatment choices and effectiveness are available for Indigenous Australians with cancer.

## Reducing Indigenous cancer mortality

Cancer mortality is high for Indigenous people partly because some cancers are more common and partly because cancer survival for most cancers is worse than for non-Indigenous people. Reducing cancer mortality requires both reduction in cancer incidence and improving the effectiveness of cancer diagnosis and treatment to improve cancer survival.

## Prevention

The cancers that are more common in Indigenous Australians are all amenable to prevention:

- the incidence of cancers of the mouth and neck, oesophagus, lung and pancreas can be reduced through reduction in tobacco consumption;
- the incidence of cancer of the cervix can be reduced through improving Pap test coverage for Indigenous women and ensuring follow-up treatment of abnormal tests by gynaecology services; and
- the incidence of cancer of the liver can be reduced by maintaining high coverage of Hepatitis B vaccination of Indigenous children for the next several decades and reducing the proportion of Indigenous people who consume alcohol at excessive levels.

Although NT Indigenous cervical cancer incidence did not decrease in the late 1990s, the fall in Indigenous Australians' mortality from cancer of the cervix in the NT after 1997 (Figure 3) may be the first indication that increasing Pap test coverage in the NT is being effective. When screening rates increase, existing undiagnosed cancers in previously unscreened women will be detected early, when they are more amenable to curative treatment. The incidence rate remains high for some time as these existing cases are diagnosed but the mortality rate falls as survival improves. Unfortunately no information is currently available on the proportion of Indigenous women having their first Pap test and the proportion of women with abnormal results, which would help to confirm whether Pap tests are being effective in this way. It is also possible that the fall in cervical cancer mortality in this relatively short period may be a random fluctuation in the number of deaths over a short period in a small population.

Improving cancer survival requires:

- improved access to primary care services for screening;
- early diagnosis;
- effective screening programs;
- effective recall and reminder systems for Pap tests;
- mammography and review of suspicious findings;
- improved access to first-line investigations such as basic x-ray facilities and to specialist services for investigation and diagnosis; and
- improved collaboration between primary care and specialist services.

There is evidence for the effectiveness of some of these strategies. The improvements that are possible through collaboration between primary care and specialist services are evident in the evaluation of the Specialist Outreach Program which commenced in 1997 in the Top End of the NT. The number of gynaecology consultations performed for women living in remote Indigenous communities increased from less than 200 in 1996 when only hospital outpatient services were available to approximately 1000 in 1999, 90% of which occurred in community health centres in remote communities. Forty-seven percent of gynaecology consultations performed by the specialist outreach service included colposcopy for follow-up of Pap test abnormalities or other cervical symptoms<sup>(36)</sup>.

Cancer treatment is primarily provided by specialist services, but for Indigenous people, both from remote areas and those living in closer proximity to specialist services, primary health care plays an important role in facilitating access to and completion of cancer treatment. This role may be in response to the consequences of geographic isolation, such as joint management of chemotherapy by oncologists and general practitioners resident in remote Indigenous communities. In all areas, primary health care services, and particularly Aboriginal Health Workers and other Indigenous staff, are involved in:

- improving communication between specialist cancer centres and Indigenous patients;
- improving understanding of the diagnosis of cancer, the consequences of that diagnosis, treatment options and risks (such as side-effects and chances of cure);
- organising attendance for treatment; and
- supporting Indigenous patients through completion of intensive cancer treatment or through palliative care.

Research in Queensland found that Indigenous women faced multiple barriers in accessing breast cancer screening, diagnosis and treatment. Indigenous Hospital Liaison Officers and Indigenous Cancer Support Officers were important to improve communication and provide support, and greater involvement of community-based health services was needed to improve understanding by women and their families of the diagnosis, treatment options and possibility of cure, to increase their involvement in treatment decisions and to provide support during treatment and follow-up<sup>(37)</sup>.

### Reducing cervical cancer mortality—an illustration based on available evidence

More evidence is available about cancer of the cervix in Indigenous women than for most other health problems, particularly for Indigenous women in the NT, and this illustrates many aspects of the interaction between Indigenous people and the health care system. The incidence rate of NT Indigenous women for cancer of the cervix is three times higher than the rate for all Australian women. There is indirect evidence that this is partly due to lower Pap test coverage; higher prevalence of cervical infection with Human

Papillomavirus (HPV) may also be partly responsible, but there is no reliable evidence of HPV infection rates for Indigenous women.

Although incidence is three times higher, the NT Indigenous cervical cancer mortality rate is nine times higher than the rate for all Australian women, because chance of cure for NT Indigenous women is much less than for non-Indigenous women. Five-year survival for Indigenous women is 50% compared to 75% for non-Indigenous women. Survival is lower for Indigenous women partly because they are less likely to be diagnosed before cancer has spread beyond the cervix, when curative surgical treatment may be effective. However, this is only part of the explanation for lower Indigenous survival. Other factors are also involved, but in the absence of research investigating the possible effect of other factors we can only speculate that delayed and incomplete treatment and the presence of other chronic diseases may be partly to blame.

All along this pathway health services could have been effective to either prevent the cancer developing, or diagnose it early and cure it. Regular Pap tests could have detected pre-malignant changes in the cervix which could have been confirmed and removed by specialist gynaecological treatment (performed in the local primary health care service and/or hospital) before invasive cancer developed. For women in whom early invasive cancer had developed, Pap test or investigation of early signs such as abnormal vaginal bleeding by primary health care services, with early referral to specialist gynaecology services, could have diagnosed the cancer before it had spread beyond the cervix; surgical treatment at this stage would have had a high chance of complete cure.

Primary health care services are crucial to reducing Indigenous cervical cancer mortality by reducing disease incidence and improving survival since they:

- educate Indigenous women about cervical cancer and Pap tests;
- offer regular Pap tests to women attending;
- operate efficient reminder and recall systems to invite women to have repeat Pap tests when they are due;
- collaborate with specialist gynaecology services to ensure all women with abnormal screening tests are assessed and treated where necessary; and
- support women who are diagnosed with cancer through the difficulties and trauma of decisions and treatment.

## Conclusion

The evidence of disease occurrence and health system performance for cancer in Indigenous Australians is incomplete but more substantial than for most other Indigenous health problems. The available evidence demonstrates that cancer has a different pattern of incidence at specific sites than for non-Indigenous Australians, and this can be partially explained by different prevalence of cancer risk factors. Indigenous survival is lower for almost all sites—partly due to delayed diagnosis and thus lower chance of cure.

The cancers that occur more frequently in Indigenous Australians are all at least partially preventable in the non-Indigenous population. Survival is much higher for non-Indigenous Australians with cancer than it is for Indigenous people, and non-Indigenous Australians' survival is continuing to improve for many of the common cancers. In New South Wales five-year survival for cancers of the breast, bowel and cervix increased by 24–35% between 1980 and 1995<sup>(38)</sup>. Health services, particularly primary health care services in collaboration with population health screening programs, an evidence-based approach to continuing improvements in specialist services, and community action to reduce behavioural and environmental risk factors, have been able to reduce the impact of many cancers in the non-Indigenous community.

The same reductions are possible for Indigenous Australians. For cancer of the cervix, total Australian mortality and incidence rates fell by over 50% in the ten years from 1990 to 2000<sup>(39)</sup>, primarily due to a more organised approach to increasing participation in cervical screening. The same reduction should be possible within an even shorter period for Indigenous women, given that a successful national program already exists. We may already have early signs that cervical cancer mortality is falling for NT Indigenous women, but it is too early to be certain that this fall will be sustained.

Evidence is available that close collaboration between primary health care and specialist services can improve health care delivery, such as the effectiveness of a specialist outreach service in improving follow-up treatment for women with abnormal Pap tests in remote communities in the NT<sup>(36)</sup>. Primary health care has an important role in all aspects of cancer control:

- Primary health care services contribute to reducing the occurrence and effect of cancer through a wide range of approaches.
- Primary health care promotes healthy behaviours to reduce individual risk of developing cancer and provides health education to increase symptom awareness.
- Primary health care promotes, facilitates and/or delivers cancer screening activities; its services provide the follow up and management required to ensure the potential benefits of breast and cervical screening are achieved through appropriate treatment, and acts as the link between screening programs and access to specialist treatment and care.
- Primary health care plays a crucial role in providing the consistency, support and information clients need to negotiate through the complexity of cancer investigation, surgery, chemotherapy, radiotherapy and other treatment, and has an important role in long-term monitoring after the completion of the initial intensive treatment phase.
- For many cancer patients and their families, primary health care is a vital part of palliative care at the end of their illness.

Cancer control requires multi-sectoral action within and involving each community, particularly for prevention and screening programs that require widespread community support to achieve legitimacy and motivate individuals to change behaviour or undergo medical tests when they feel fit and well. Early presentation with symptoms and completion of investigations and treatment similarly requires widespread community understanding of cancer symptoms and confidence that health services will do more good than harm. The barriers of culture, language, education and historical experience between many Indigenous people and the health care system mean that for Indigenous people more than most, primary health care services (particularly Aboriginal community-controlled health services) play a pivotal role in the collaborations required between all health care sectors and Indigenous people. Primary health care services in Indigenous communities provide the conduit through which almost all other health services reach Indigenous people. Primary health care services act as the facilitator and negotiator for many Indigenous people into the complexity of specialist services for investigation and treatment of cancer, helping to overcome the remoteness of many specialist health services and the barriers of culture, language, comprehension and trust. Screening and health promotion services similarly require the primary health care services in a community to provide legitimacy within the community and facilitate interaction with community organisations and members.

The experience of Indigenous people and cancer provides evidence that the Australian health system is not operating as effectively for Indigenous as other Australians, but there are indications of improvements such as increasing Pap test participation and the effectiveness of specialist outreach programs, which may already be reducing cervical cancer mortality for Indigenous women. Primary health care services are central to

these successes. Strengthening primary health care services, reducing barriers for access to specialist services and improving collaboration between the two are essential to continuing these early improvements for cervical cancer, and for extending these successes to other cancers and the many other health problems of Indigenous people throughout Australia.

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