

# Reducing the impact of cancer in Indigenous communities: ways forward

Ray M Lowenthal, Paul B Grogan and Ellen T Kerrins

Indigenous Australians with cancer are twice as likely to die from the disease than non-Indigenous Australians. Because of this stark imbalance, the Cancer Council Australia recently convened the first-ever national discussion forum to address the issue.

About 120 people from around Australia gathered in Darwin in August 2004 for the forum, "Reducing the impact of cancer in Indigenous communities: ways forward".

Originally conceived by the Cancer Council Australia as an internal event, planning for the forum tapped into a ground swell of concern about the poor outcomes for Indigenous Australians with cancer. This interest, combined with financial support from the Australian and Northern Territory governments, the National Cancer Control Initiative and the Cancer Council Northern Territory, turned the meeting into a major national event.

## Why a discussion forum?

The past two decades have seen a 30% reduction in cancer mortality rates in Australia. However, at a meeting in late 2003, the board of the Cancer Council Australia reflected on the fact that recent successes in cancer control were not shared by Indigenous Australians and that we did not fully understand why.

We were familiar with the rhetoric about limited access to services, cultural barriers and coexisting health problems, but, before we could work towards improving Indigenous cancer outcomes, the problems needed to be better understood.

To this end, we invited Australia's leading oncologists and epidemiologists with an Indigenous focus, academics, Aboriginal health workers and Indigenous cancer survivors to the forum. Organisational support from the National Aboriginal Community Controlled Health Organisation (NACCHO) helped us reach Aboriginal health workers from Australia's most remote communities. The result was an unprecedented sharing of epidemiological, cultural and anecdotal Indigenous cancer data, with consensus on ways in which stakeholders could work together to effect measurable improvements.

## Epidemiology

There is no simple answer to the question of why Indigenous people with cancer die at twice the rate of other Australians with cancer, nor is there a national dataset from which to draw. The inadequacy of

data itself demonstrates the extent to which the problem has been overlooked.

However, information gathering on a state and territory basis is improving significantly, particularly in South Australia and the Northern Territory. David Roder (Head of Epidemiology, Cancer Council South Australia) and John Condon (Senior Research Fellow, Menzies School of Health Research) explained that the comparatively high mortality rate is partly the result of Indigenous Australians getting "more than their share" of cancers with poorer survival outcomes, such as cancers of the lung, oropharynx, oesophagus, liver, gallbladder and pancreas. Conversely, Indigenous Australians have lower rates of some of the more curable cancers, such as breast, prostate, bowel and skin cancers.

Delayed diagnoses in Indigenous people also contribute to poor survival rates, along with a reduced likelihood of completing treatment. These problems may explain why Indigenous Australians die at higher rates than other Australians, even when afflicted with the same cancer type. However, the forum also revealed other, less apparent factors.

## Penetrating insights

Ngiare Brown (an Aboriginal medical educator and child health specialist with the NT Government) cited institutionalised racism, bureaucratic inaction, and a disconnect between Indigenous and non-Indigenous Australians as the underlying reasons behind the so-called "double burden" of disease suffered by Indigenous people. Brown also reminded the forum of other statistical inequities: twice the rate of low birthweight, and an overall life expectancy 20 years less than that of non-Indigenous Australians.

A penetrating cultural insight came from Jeremy Baker Balung (an Indigenous man who works as a counsellor for Aboriginal and Torres Strait Islander cancer patients at Royal Darwin Hospital). Among Baker Balung's Yolgnu people, 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. He emphasised the need to respect such beliefs, which are underscored by a deep regard for kin. A person who believes his or her cancer is "payback" for offending a family member may not pursue treatment. Respect and understanding must be reciprocal for people with such strong spiritual convictions; medical practitioners dismissive of time-honoured traditions may be unable to gain their patients' trust.

Cultural differences go hand in hand with communication barriers. For many Indigenous people, English is the second, third or fourth language, with multiple native dialects predominating in more remote communities. NT epidemiological data show that treatment outcomes are consistently poorer for all cancers in people whose first language is an Indigenous language.

## Access and distance

Cancer is a difficult disease to treat remotely, and many Indigenous people live vast distances from urban centres. Sid Selva (Oncologist,

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Royal Darwin Hospital) described treating patients for whom arduous travel exacerbated the disorientation already induced by their diagnosis. The fact that Selva is the only resident medical oncologist in the "Top End" underscores a general problem with service provision in regional Australia.

Michael Barton (Deputy Director of Radiation Oncology, Liverpool Hospital), who is author of a study of radiation services in the Northern Territory, expanded on the problems of distance, a reminder about the immobile and high-maintenance nature of radiotherapy hardware.

Such problems reflect overall challenges for healthcare delivery in rural and remote Australia, which are compounded by the cultural, linguistic and socioeconomic barriers unique to Indigenous communities.

Jacinta Elston (Associate Professor of Indigenous Health, James Cook University), herself an Aboriginal woman undergoing cancer chemotherapy, described the practical hurdles for anyone on the cancer journey and explained how they are considerably greater for most Indigenous people: 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, particularly for people already at the margins of Australian society.

### Ways forward

The forum sought "ways forward", and the discussions and workshops mapped out paths towards improving the poor cancer outcomes for Indigenous people.

Consistent throughout was the need for allied health agencies to form collaborative partnerships with Indigenous organisations and individuals. Our ignorance of complex yet imperative cultural and linguistic issues was laid bare at the forum and supported by the latest data. Only by engaging with people like Jacinta Elston and Jeremy Baker Balung in interface roles will we be able to break down these barriers.

In response, the Cancer Council Australia is inviting Indigenous representatives to join its principal committees, is seeking to co-opt an Indigenous Australian onto its board, and is discussing a memorandum of understanding with NACCHO.

Options will be examined to boost research on cancer in Indigenous people, ensuring it is undertaken with liaison officers and developed in ways that will give ownership of the data to Indigenous people, many of whom have reason to be sceptical about research given the history of European paternalism.

Increased collaboration should be enhanced by efforts to build the capacity of the Aboriginal health workforce. Much will depend on government funding, and improved cancer control in Indigenous communities has now become a key cancer council advocacy goal. The signs are encouraging: the Coalition's pre-election cancer policy included a national bowel cancer screening program, targeting Australians aged from 55 and Indigenous Australians aged from 45, indicating a shift towards policy adjustments consistent with the poorer health outcomes of Indigenous people.

Cancer councils and their allies will also work towards factoring Indigenous issues into policy development and promotion at every step in the cancer journey, from prevention to palliation.

There is no better example of the challenges of cancer prevention than smoking prevalence: 50% of the Indigenous population smoke, compared with about 20% of non-Indigenous Australians. To reduce this figure, again we must connect with Indigenous people

and involve their organisations and communities in spreading the public health messages.

The need to formally involve Indigenous people in service design and delivery also applies to cancer screening programs. Already there are signs of improvement, with targeted Pap smears contributing to a 50% fall in Indigenous cervical cancer mortality in the late 1990s.

Palliation is also critical, particularly among people with such high rates of mortality and premature death. The Cancer Council Australia will look at educational tools to assist in the management of pain, dying and death among Indigenous communities.

Our commitment is already well supported at state and territory level. The Cancer Council New South Wales' recent employment of an Aboriginal liaison officer based in Dubbo and the release of a cancer information kit for Aboriginal health workers are excellent initiatives that could be applied nationally.

These are all small steps towards a distant destination. But only through setting and achieving shorter-term goals will we be able to make an impact on the appallingly poor state of cancer outcomes for Indigenous Australians.

The discussion forum reiterated the overarching themes of dispossession, hopelessness, grieving, racism, paternalism and abject socioeconomic status — seemingly insurmountable problems, but not when addressed with the sense of purpose, cooperation and strategic thinking evident at the recent national forum.

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