

# Reducing the burden of cancer for Aboriginal and Torres Strait Islander Australians: time for a coordinated, collaborative, priority-driven, Indigenous-led research program

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The burden of cancer for Aboriginal and Torres Strait Islander (Indigenous) Australians has only recently begun to be appreciated. Perhaps this is not surprising, given the large number of health conditions that are many times more common among Indigenous Australians than among other Australians. Deaths from diabetes, kidney disease and heart disease occur at, respectively, about 13, five and three times the rates at which they occur in the Australian population,<sup>1</sup> and these diseases are rightly seen as priorities in Indigenous health. Cancer deaths occur at “only” about 1.6 times the rate they occur in the Australian population,<sup>1</sup> but cancer survival is lower for Indigenous people. Cancer is the third most common cause of death among Indigenous Australians, and accounts for a greater number of deaths each year than diabetes and kidney disease.<sup>1</sup> Indigenous Australians experience a higher incidence of high-fatality cancers, their cancers tend to have reached more advanced stages at diagnosis, and they have greater levels of comorbid illness, poorer access to care and less comprehensive treatment.<sup>2,3</sup> In addition, many potentially preventable or screen-detectable cancers are more common among Indigenous Australians.<sup>2,3</sup>

Complicating these figures is the fact that many Indigenous cancer patients are not identified as such in the state and territory cancer registries that are the key sources of basic statistical data on cancer patterns.<sup>1-3</sup> This means that the burden of cancer among Indigenous Australians continues to be underestimated.

This broad picture suggests a widespread failure of the health system to prevent, diagnose and treat cancer among Indigenous Australians.<sup>2,3</sup> Although the need to improve cancer-related health services for Indigenous Australians is apparent, the available evidence is currently inadequate to direct such efforts. For example, we know little about the availability of Indigenous-specific cancer support services,<sup>4</sup> which models of care are most effective, or the needs of Indigenous cancer patients and what their families need to do in order to engage productively with health services.<sup>5</sup> Neither do we know enough about the potentially modifiable factors related to health services design and delivery that are associated with poorer cancer outcomes. For many Indigenous people, cancer is seen as a death sentence and treatment is therefore not always regarded as a high priority.<sup>6</sup> Competing social, cultural and family demands as well as inadequate communication between health service providers and Indigenous people may also result in less comprehensive cancer treatment.

In order to improve the performance of the health system for Indigenous people with cancer, we need to know more about what works, and we need to ensure that such knowledge influences policy and practice. Although there have been improvements in some areas affecting cancer outcomes for Indigenous Australians (eg, greater attention to the cultural sensitivity of screening programs<sup>3,5</sup>), there has not been a national effort to measure the effects of these and other interventions, nor sufficient research to guide priorities. For example, one of the most obvious ways to improve Indigenous

## ABSTRACT

- Australia's efforts to prevent, diagnose and treat cancer are not as successful for Aboriginal and Torres Strait Islander people as they are for other Australians.
- There is a need for a nationally coordinated, collaborative, priority-driven research effort to better understand what works, and we need to implement that knowledge.
- All aspects of the process must involve genuine Indigenous leadership and participation.

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health is to reduce smoking, yet until recently,<sup>7</sup> there have been few resources dedicated to Indigenous tobacco control programs, and even fewer to enable the success or otherwise of such initiatives to be evaluated.<sup>3</sup> Recent developments suggest that the time is right to make substantial gains through a coordinated, priority-driven research effort. This should involve a collaborative partnership of researchers, policymakers, service providers and consumers, with substantial Indigenous input and leadership.

In December 2010, the Lowitja Institute, Australia's National Institute for Aboriginal and Torres Strait Islander Health Research ([www.lowitja.org.au](http://www.lowitja.org.au)), in partnership with the Queensland Institute of Medical Research (QIMR), sponsored the National Roundtable on Priorities for Aboriginal and Torres Strait Islander Cancer Research conference. Leading cancer experts, Indigenous cancer survivors and Indigenous community representatives shared information about current research findings and tools, and about expertise in Indigenous cancer research. Attempts were made to clarify achievable, collaborative national research priorities for better outcomes for Indigenous people with cancer and their families and communities.

The National Roundtable built on momentum that has been growing slowly but steadily over the past decade. In 2003, the first review of cancer in Indigenous Australians highlighted its importance and identified the relative paucity of relevant research work.<sup>8</sup> In 2004, the Cancer Council Australia, the peak non-government body composed of state and territory cancer councils, convened the first national discussion forum on Indigenous cancer.<sup>9</sup> Throughout the decade, research groups undertook important work relating to health system performance for Indigenous people with cancer,<sup>2,3,5,10-12</sup> but they largely worked in isolation from one another.

In 2007, *Lancet Oncology* commissioned a review of cancer in Indigenous Australians,<sup>2</sup> a much needed update to the 2003 review.<sup>8</sup> In 2010, Cancer Australia, a federal government agency formed in 2006 to drive national efforts in cancer control, commissioned a comprehensive review of research and other initiatives relating to cancer control in Indigenous Australians.<sup>3</sup> Members of Cancer Australia's Aboriginal and Torres Strait Islander working group were included in the review project's steering

group. The review provided a summary of the evidence and made 31 recommendations.<sup>3</sup> Subsequent discussions between QIMR, the Lowitja Institute, members of the review team and a range of other stakeholders resulted in the convening of the National Roundtable.

Based on the discussions of National Roundtable participants, there appears to be substantial agreement about what is needed for productive progress. First and foremost, the involvement and leadership of Indigenous people is critical. Second, we need to work collaboratively and share lessons between jurisdictions, institutions, researchers, policymakers, service providers and consumers. Third, we need to clearly articulate shared research priorities, emphasising work in:

- reducing risk (eg, effective tobacco control);
- identifying and implementing strategies that work in preventive, diagnostic, therapeutic and palliative services;
- engaging Indigenous people and communities;
- improving cancer health literacy; and
- improving basic data infrastructure and monitoring capability to measure progress and improve cancer care delivery.

National Roundtable participants envisaged a nationally integrated and coordinated approach, in which new research builds systematically on what has already been done, with audit, feedback and translation into behaviour as integral parts of the process.

An overarching governance arrangement was suggested to address issues of strategic priorities and translation of collective results of research to ensure its relevance and benefit. Indigenous ownership of this governance arrangement, as opposed to a “top down” government approach, was seen as crucial, as was partnering with experts in relevant disciplines.

It was also agreed that the research agenda needed to be led by Indigenous people, with its direction focusing firstly on cancers with the largest gaps in survival. The realities of the “patient journey” (eg, transport problems, racism, the broader social determinants affecting an individual, and the importance of a support person) could be used to assess the effectiveness of future interventions.

Lastly, National Roundtable participants envisaged a move away from state- or territory-based approaches or specific cancer-based approaches towards more integrated, coordinated, systems-based approaches to improve the quality of care. It was agreed that there is an urgent need to identify the barriers against and enablers for accurate identification of Indigenous status to improve accuracy of data collection. We need to ensure that the internationally competitive level of cancer management available to many Australians is also accessible and culturally appropriate for Indigenous Australians.

It appears we now have a critical mass of people who understand what needs to be done and who want to work together to make it happen. Indeed, a large coalition of researchers, policymakers, service providers, consumer advocates and Indigenous leaders is currently seeking funding to establish an integrated program of applied research, stakeholder engagement, knowledge transfer and training, based on the principles outlined above. Such a collaborative effort would provide a much needed boost to our individual efforts to improve Indigenous cancer control. We must not squander the opportunity to make a lasting difference.

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### Competing interests

None identified.

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