

Supporting cancer control for Indigenous Australians: initiatives and challenges for cancer councils

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Abstract

As in other developed countries, the Australian population is ageing, and cancer rates increase with age. Despite their substantially lower life expectancy, Indigenous Australians are also experiencing concerning cancer statistics, characterised by increasing rates, later diagnosis, higher mortality, and lower participation in screening than the non-Indigenous population. Eighteen months after the first national Indigenous Cancer Control Forum, this environmental scan within the state-based Cancer Councils was undertaken to map activities in service provision in Indigenous cancer control with a view to sharing the lessons learned. The findings show that although most of the organisations had tried to work with Indigenous communities on cancer issues, there have been difficulties in building and sustaining relationships with Indigenous organisations. Lack of having Indigenous staff internally, few Indigenous-specific resources, and few planned, long-term commitments were some of the major impediments. Some of these limitations can easily be overcome by building and improving regional or local partnerships, providing cultural awareness training to internal staff, and by building the capacity of Indigenous organisations. Health promotion projects of the Cancer Councils directed at Indigenous people could be more effectively implemented with such considerations.

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What is known about the topic?

For many years cancer was not considered a high priority issue for Indigenous Australians as a consequence of social and other health issues. Cancer incidence and death rates of Indigenous Australians have been unclear as there has been limited epidemiological information and misclassification of Indigenous status. It is now evident that the pattern of cancer differs for Indigenous Australians, and Indigenous people tend to be diagnosed later, have poorer participation in treatment and a higher mortality rate for any equivalent stage of diagnosis.

What does this paper add?

This paper presents a snapshot of the staffing, projects, programs and activities of the state Cancer Councils in early 2006 in terms of efforts to progress cancer control issues focussing on Indigenous Australians. Most successful initiatives began by establishing a relationship and working over the longer term to sustain program activity.

What are the implications for practitioners?

Insights from the analysis of progress in the cancer field are relevant and applicable to practitioners in other areas of health where mainstream services have a role to improve the health of Indigenous communities.

THE NUMBER OF recorded cancer deaths in Australia continues to increase, attributed in part to the increase in cancer incidence that occurs in an ageing and an expanding population.^{1,2} Until recently, cancer was seldom identified as a priority health issue for Aboriginal and Torres Strait Islander (hereafter Indigenous) Australians.*³ The immediate health and welfare problems of Indigenous Australians across the lifecourse are well documented,⁴⁻⁶ and these may have distracted attention from the fact that cancer has

*Australia has two groups of Indigenous populations: Aboriginal, and Torres Strait Islanders. In this paper, we will use the term "Indigenous" to refer to both Aboriginal and Torres Strait Islander peoples.

become one of the major causes of death for these people. Interest about cancer among Indigenous populations may also be affected by their lower incidence of many cancers and their shorter life expectancy. Moreover, cancer rates in Indigenous Australians may under-represent the real burden because of misclassification and under-ascertainment of Indigenous status.⁷⁻⁹

Nevertheless, available data show that Indigenous Australians are experiencing an increasing rate for some cancers.³ For almost all cancers, they experience later diagnosis, lower 5-year survival and a higher mortality rate than non-Indigenous Australians.¹⁰ Indigenous women have lower participation in mammography and Pap smear screening than non-Indigenous women.^{11,12} It has also been reported that the overall response rate was significantly lower for Indigenous people than the general population in the Bowel Cancer Screening Pilot Program that ran between November 2002 and June 2004 at three sites in Australia.¹³ Moreover, while the last two decades have seen a 30% reduction in cancer mortality rates in Australia, there has been little impact upon Indigenous cancer mortality.¹⁴ The need to prioritise cancer prevention and control was recognised in the National Indigenous and Torres Strait Islander Health Strategy 2001, where cancer was documented as one of three major chronic diseases for Indigenous Australians.¹⁵

The first national forum to discuss Indigenous cancer issues, held in Darwin in August 2004, highlighted various gaps that exist around responding appropriately to these issues. Many strategies were proposed to improve their poorer cancer outcomes. Increased government funding, boosting research on cancer among Indigenous Australians by enhancing their ownership over the data, and involving them in partnership with non-Indigenous health professionals to ensure appropriate service design and delivery mechanisms were a few of the significant recommendations. At the conclusion of the forum, the peak non-government organisations providing advocacy for prevention and care for cancer in Australia, The Cancer Council Australia and its state-based affiliates, committed to factoring Indige-

nous issues into their policy development and advocacy for cancer prevention and care.¹⁴

This paper summarises the findings of an environmental scan of current and past programs and practice in Indigenous cancer control by state and territory member organisations of The Cancer Council Australia. It was primarily undertaken to inform the deliberations of The Cancer Council Western Australia (TCCWA) on its potential role and contribution in improving cancer-related services for Indigenous people in WA. Environmental scanning is a method most commonly used in business but is quite popular in the health care sector around the world,¹⁶⁻¹⁸ and is used to identify emerging issues within the broader economic and political environment.¹⁹ It is similar to situation analysis in which a review is undertaken of health strategies and policies, institutional support systems, programs and interventions with the aim of strengthening health reform and health systems. It differs from audits which generally evaluate performance and are aimed at ascertaining the validity and reliability of information as part of quality control processes. Morrison argues that environmental scanning is a method that enables decision makers both to understand the external environment and the interconnections of its various sectors and to translate this understanding into an institution's planning and decision-making processes.²⁰ The advantage of environmental scanning for organisational leaders is that knowing both the internal and external environment in which the organisation operates is helpful in planning their future course of action.²¹

The scan was undertaken to identify various Indigenous-specific programs and experiences of the Cancer Councils of Australia 12–15 months following the Darwin forum. This paper highlights the key issues, learning, successes and limitations of related initiatives that have been undertaken by the state Cancer Councils.

Methods

Environmental scanning was agreed to be a suitable method for learning about how a range of organisations across the sector had approached

Summary of progress in organisational and program initiatives for indigenous cancer control by participating jurisdictional Cancer Councils, March 2006

	Jurisdiction						
	ACT	NSW	Qld	SA	Tas	Vic	WA
Organisational							
Indigenous person employed	No	Not current	No	No	No	Yes	No
Position with specific Indigenous focus	No	No	No	Yes (0.2 FTE)*	No	Yes	No
Cultural awareness training	No	Yes	Yes	No	No	Voluntary	No
Specific Indigenous action plan	No	No	Recent	No	No	Tobacco, Cervical screening	No
Indigenous person on board	No	No	No	No	No	No	No
Indigenous representation on working parties	No	Yes	No	No	No	Yes	No
Links with ACCHOs	Strong	Beginning	No	Yes	No	Yes	Ad hoc
Specific programs							
Cancer awareness/health promotion at Indigenous events	Yes	Yes	Yes	Yes	No	Yes	Yes
Tobacco control	Sustained	Yes	Yes	Yes		Sustained	Yes
Cervical screening			Limited	Yes		Funds VAHS +	
Breast cancer awareness			Ad hoc				Ad hoc
Aboriginal health worker training		Yes	Yes			Yes	
Cancer support and care			Yes	For women			
Speakers	No		Yes				No
Indigenous-focussed resources	Limited	Limited	Yes	Limited	Limited	Yes	Beginning
Data on Indigenous cancer statistics	No	Yes	Beginning	Yes	No	Yes	Yes

* A non-Indigenous person spends 1 day a week on Indigenous cancer issue. ACCHOs = Aboriginal controlled community health organisations.

supporting Indigenous cancer control approaches and gathering information about successful initiatives and efforts that had been less productive, and this approach was accepted by a Steering Committee and approved by the Curtin Health Research Ethics Committee.

An initial approach letter was mailed to the Chief Executive Officers/Directors (CEOs) of all the Cancer Councils, outlining the background to the survey. They were also requested to nominate appropriate staff members who could be interviewed about their organisations' past or present

initiatives to improve Indigenous engagement with cancer issues and to pass the background information about the study on to those they nominated. When the individuals were contacted and nominated others, these additional nominees were also interviewed if available and willing. A copy of the letter sent to their CEO was provided to the participants beforehand.

Semi-structured interviews, either face-to-face or by telephone, were undertaken with the key nominated staff (Indigenous and non-Indigenous). The interview was based upon a theme list

developed following a review of relevant literature and discussion within the research team. The list was also discussed with Indigenous colleagues and forwarded to a Steering Committee established to oversee the project of which this scan was a component. Key areas focusing on Indigenous Australians that were considered during the interviews, included: cancer prevention and education; cancer support services for Indigenous health organisations; health care delivery (workforce/access to health care services); research; advocacy/policy and human resources and any cross-organisational initiatives. Interviews were taped with the permission of participants, and the responses were coded following the key themes of the interview schedule. Thematic analysis was undertaken manually, in which the efforts and experiences of each Cancer Council were recorded against the major service areas.

Staff from The Cancer Councils of the Australian Capital Territory, Tasmania, Victoria, New South Wales and the Cancer Foundation of Queensland participated in telephone interviews. Information was collected from staff at the Cancer Councils of Western Australia and South Australia through face-to-face interviews. Before submission of this article for publication, it was circulated to the CEOs of all participating Cancer Councils, giving them the opportunity to make additions or corrections, and appropriately represent their organisation, and suggested amendments were incorporated.

Findings from the scan

Most interviewees indicated that their organisation had tried to work with Indigenous communities on cancer-related issues. Working in partnership with Indigenous organisations was seen as important, and perhaps more effective than establishing Indigenous-specific positions within the organisation. However, a number of respondents noted the difficulty of building and sustaining relationships with Indigenous health agencies because they were under-resourced to respond and cancer is not prioritised among many competing social and health issues. Key

findings related to Indigenous cancer control are summarised in the Box. Further details are reported according to core functional areas.

Education and training

Capacity building within the Indigenous health sector was identified as a priority area, in which respondents believed Cancer Councils could play an important supportive and advocacy role. Some success was reported in running training programs with Aboriginal Health Workers (AHWs). The most promising example was initiated by The Queensland Cancer Fund (QCF). Based upon the priorities identified through consulting Indigenous groups and other key stakeholders, a cancer care course was developed for AHWs with assistance from an Indigenous advisory panel in developing the course content. The five-day program introduced various aspects of cancer treatment and care, and provided site visits to various cancer support services. Overall, it was felt the course provided a good overview for the AHWs on the rationale and practical aspects of cancer treatment and insight into what patients go through during treatment. Scholarships were provided to 14 health workers from across Queensland to attend the first course, and this helped with the development of networks between AHWs and cancer service providers. Indigenous participants were generally identified through the regional officers of the QCF and contact with Indigenous communities. The desirability of one-to-one follow-up and support after training, utilising regional officers, was emphasised. The QCF has also trialled a less intensive version of education, for example, by adapting a mainstream 2-day training program for community speakers around prevention and awareness of cancer for delivery to AHWs in northern Queensland. A small number of volunteer Indigenous speakers were trained through this program to increase cancer awareness in their local communities.

Cancer Councils in some other jurisdictions have also tried to arrange training programs with AHWs, although some reported receiving a low level of interest from the stakeholders. TCCWA regularly contributes to teaching around cancer

within metropolitan-based AHW training. Others, in partnership with Indigenous Community Controlled Health Organisations in their areas, have begun planning to incorporate cancer awareness into AHW training, but not all discussions have yet resulted in established commitment. The Cancer Council Victoria (TCCV) has, since 2001, been delivering training on cancer, screening and cervical cancer to AHWs undertaking the Certificate 4 in Women's and Babies' health which is delivered by the Victorian Aboriginal Community Controlled Health Organisation.

The Cancer Council New South Wales (TCCNSW) had organised one-day training workshops for AHWs covering basic information about cancer biology, prevention, early detection, treatment and end of life which were jointly delivered by two Aboriginal consultants. However, the workshops have not been systematically and regularly conducted. The organisation now proposed to develop a more sustainable, organised program with regional Aboriginal Health Services (AHSs) interested in this approach. Implementation may occur by extending the 1-day training workshop to 2 days, and shifting the focus to include more practical issues related to cancer care.

Lack of availability of Indigenous-specific resources was mentioned as a barrier to education about cancer. TCCV has supported development of many Indigenous-friendly resources addressing smoking cessation and cervical screening. Respondents were also aware of resources in the process of development by other organisations such as The Centre for Excellence in Indigenous Tobacco Control, and felt that specific resources would be helpful in address Indigenous needs. It was considered important to develop educational and outreach materials that included artwork, pictures, role models and/or stories resonating culturally with the program's target population. It was also stressed that any resources produced must be appropriately used, because in some instances, good resources remain under-utilised as a result of inadequate promotion, poor distribution or inadequate staff training in their appropriate use. Although there was recognition that resources designed in another jurisdiction were

not always suitable and relevant elsewhere, some respondents noted a lack of capacity within their organisations in adapting these or developing new resources.

Education of cancer staff about Indigenous people

Training and capacity building are not only necessary for AHWs and community members. Respondents acknowledged the need for awareness of Indigenous culture, cultural differences and beliefs to be taught and understood among the mainstream health service providers. The QCF runs cultural awareness training for staff twice a year, with training provided by the Department of Health and delivered by an Indigenous person. The TCCNSW has been running 2-day workshops on Indigenous culture for about 5 years, and it is mandatory for all staff. TCCV have organised cultural awareness training in 2001 and 2005, and they now plan to deliver it annually.

Cancer prevention education

The focus within cancer prevention was strongest in the area of tobacco control, and primarily focussed on education and support initiatives. For instance, TCCWA provides support and advice to Say No To Smokes, the only Aboriginal-targeted tobacco control project in WA. Working in collaboration with the Say No To Smokes team, the partners have now submitted a joint funding proposal for another project, the brainchild of an Aboriginal ex-smoker, to capture and tell in their own words the success stories of Indigenous people who have stopped smoking. The Australian Capital Territory Cancer Council in partnership with Winnunga Nimmitjah runs a smoking cessation program No More Bunda for Indigenous people that includes access to free nicotine-replacement therapy (NRT). This program was adapted from a standard cessation program and has been running for 5 years. TCCV is working in two program areas — tobacco control and cervical screening — to take on an Indigenous-specific focus, and to train and support AHWs. TCCSA supports and plays partnership roles with the

Aboriginal Health Council of South Australia to deliver a Quit Skills training program to AHWs. TCCNSW appointed an Indigenous representative on the planning committee for a tobacco control conference and provided 12 scholarships for Indigenous people to attend.

In reporting on successful initiatives, respondents often described relatively small-scale local or regional initiatives where the kernel of the project came out of a personal or good relationship between a Cancer Council member and an Indigenous person working in a local health service or in the community. Such partnerships recognised that Indigenous Health Services are experienced in working with Indigenous people, while the Cancer Councils have expertise around cancer education and supporting people affected by cancer. Building relationships and reciprocity through sharing information and skills between organisations was valued by the informants. A local or regional approach was seen as better able to support the diverse needs of the Indigenous population within each state.

Indigenous employment

Involvement of Indigenous people was acknowledged as a crucial factor in every aspect of cancer-related service delivery. However, only one of the Cancer Councils (TCCV) during the project period reported having an Indigenous staff member. While some Cancer Councils had experience in recruiting Indigenous staff, respondents recognised the inherent problems of appointing one Indigenous position to provide advice across the organisation. Based upon their observations and experience, respondents believed that it was difficult to recruit Indigenous staff with the skills and knowledge to hit the ground running. One respondent proposed the merits of two or three part-time positions working together on one project instead of one person across the whole organisation.

Respondents were aware of the need to provide orientation, adequate direction and support to Indigenous staff in the same way as other staff members, but some noted that there had been difficulties in achieving this in practice. There

were risks of Indigenous staff members feeling isolated, and either not performing to their ability or suffering burnout. Some respondents proposed the need to encourage Indigenous employees to network with other Indigenous people in the health sector if there were not other Indigenous employees within the organisation. In the absence of Indigenous staff members, some organisations are working with Indigenous volunteers and some with non-Indigenous staff, generally through linking with Indigenous health service organisations.

Policy and advocacy

The need for Indigenous people to be involved in setting the agenda and deciding priorities was consistently recognised by the respondents — as it is in the literature. But respondents also acknowledged that initiatives would have to fit within the Cancer Councils' scope and priorities. Cancer Council staffs are aware of their reliance upon donors and fundraising events, and were cautious about undertaking activities that might offend donors or distract from their mainstream business. A number of the informants described their organisation as "white middle class", not intended as criticism but rather as a statement of where they were in their historical development. In some jurisdictions, programs for culturally and linguistically diverse populations were also acknowledged as relatively under-developed. The Cancer Councils generally had not adopted specific Indigenous action plans, although they had strategic plans that addressed social determinants of health inequalities, special needs groups and under-served populations.

Informants generally felt that insufficient time and effort had been put into Indigenous cancer issues within their organisations to date. What had been undertaken was described by some as piecemeal, "just scratching the surface". There were some criticisms that efforts had not generally been sustained over time. For example, one respondent reported that their organisation had been running programs like a 1-day workshop on Quit skills to raise awareness; promoting discussion about priorities and areas for action to

support Indigenous cancer support group; running projects with young Indigenous women smokers to quit smoking and so on. However, systematic efforts with follow through have only recently begun, and are still at an early stage of development. Some Cancer Councils have established a staff Aboriginal Health Interest Group. At TCCV a voluntary group with representatives from most Units was established in 2002 and meets quarterly to discuss Indigenous issues, provide cultural awareness opportunities and links with external Aboriginal health agencies. The group enables increased awareness of Indigenous needs and information goes back to Units to address.

Cancer support services

Cancer support services provide support across a range of needs to people during their cancer journey, from counselling newly diagnosed cancer patients, their families and friends, to providing emotional and practical support, advice, accommodation and assistance with palliative care. None of the Cancer Councils reported that Indigenous people were truly represented in their client groups. However, TCCSA had supported the establishment of an independent Indigenous Women's Cancer Action Group that provides support to other women with cancer.

Underlying issues for inclusion of Indigenous people in cancer care and support emerged during the interviews. With regard to accommodation facilities, some informants reported there had been tensions related to large families visiting and staying, mess, dirtiness and noise. It was widely reported that many staff felt ill equipped to deal with the cultural differences of Indigenous patients, and some staff were uncomfortable in dealing with Indigenous families. They did not understand the values and customs of Indigenous people, while language difficulties further impeded communication. Often there was no access to interpreters when the person spoke an Aboriginal language as their first and usual language. There were also issues with some Indigenous clients not wanting to be alone in private rooms, preferring being at floor level rather than

bed height, having different dietary preferences and their preferred foods being unavailable. Despite challenges in communication, staff often understood the desire of rural patients to return home to die, but it generally had required dedicated effort and substantial cost to achieve this.

A number of informants spoke of the importance of improving the quality of data around Indigenous cancer and needs. Good information serves as the impetus for setting priorities and directing resources, giving individuals a rationale for further work with a minority population. Baseline data for monitoring progress was seen as vital for people in the field.

Discussion

Cancer Councils in Australia have been highly effective non-government organisations with considerable expertise on all aspects of cancer control. As a result of their strategic approach, they are effective advocates around cancer screening, treatment and support services. As key players in cancer control, they contribute through education, training, research, advocacy and cancer support service functions, all of which are necessary components of achieving improved cancer-related outcomes for Indigenous Australians.

Cancer Council staff acknowledged the limitations of their organisations in addressing Indigenous cancer issues and their own deficiencies in understanding Indigenous culture and hence the "right" way to do things. But their willingness and enthusiasm to work with these communities was apparent in the organisation and participation at the 2004 Indigenous Cancer Control Forum in Darwin, and this was followed by new initiatives within many of the Cancer Councils. These initiatives include planning for a state-based Indigenous Cancer Forum in South Australia (held in September 2006), training of AHWs, cultural safety training for non-Indigenous cancer support staff, and working in collaboration with local and regional Indigenous health organisations.

Limitations identified in the environmental scan which impeded progress on Indigenous cancer issues were the lack of dedicated staff time

for Indigenous issues, lack of Indigenous staff, limited commitment of significant resources on a sustained basis, and lack of Indigenous input into policy and programs. There were no Indigenous Board members, and where an Indigenous person had been appointed as a staff member, often many demands were made upon them. Some were uncomfortable working in a mainstream organisation without Indigenous colleagues providing peer-support. While it was recognised as desirable to have Indigenous staff members working within the organisations, respondents appreciated the practical challenges of this, and that an Indigenous person *per se* was not a panacea. Most organisations therefore opted to develop linkages with Indigenous health organisations, and in some instances such projects had been sustained over a number of years, with resources committed over that time period. The linkage approach sometimes proved frustrating as it often relied upon individual relationships and required that the Indigenous organisation have both capacity and commitment to the partnership.

Informants recognised the necessity to build capacity around cancer within the Indigenous health sector. Considerable activity, not all of which had yet come to fruition, had been initiated at planning and service levels subsequent to the Darwin forum, and the project funded by TCCWA, of which this scan is a component, exemplifies the interest in how Indigenous cancer control might be progressed. An intensive week of training with ongoing opportunities for networking and relevant professional development seems a particularly useful approach to increasing Indigenous capacity around cancer issues.

Activities and projects catalysed by small seed project funding and initiated regionally or locally within established networks, were often cited as successes. However, such successes had not generally been translated into sustained activity or programs. Participants consistently recognised the importance of long-term and well planned programs with dedicated resources.

Practitioners involved in health promotion with Indigenous clients advocated the use of “non-preachy” methods, that is, approaches that appeal

to an individual’s concern for the health and wellbeing of their family and the community rather than harms to their own health. Thus, messages around tobacco control might focus initially upon harm reduction by preventing passive exposure of family members to tobacco smoke.

Cancer Councils provide support services for people with cancer that recognise the social, spiritual, emotional, and physical supports of cancer patients and their family members. However, most were aware of their own organisational limitations in understanding and capacity, particularly around Indigenous culture and values. Although there has been very limited exploration in Australia of what cancer means to Indigenous Australians, those interviewed recognised that Western psychosocial and support models might not be appropriate for Indigenous clients. This deficit in understanding made service providers feel that they lacked the knowledge and confidence in supporting Indigenous clients well. Staffs were keen to better appreciate Indigenous people’s socio-cultural understanding of cancer and to use this knowledge in their practice in cancer service delivery. Many would welcome Indigenous cultural awareness training but wanted specific information around cancer beliefs, not just information about the historical context of Indigenous health.

Although Cancer Councils have a well developed network of volunteers to help support people with cancer, training of existing staff and volunteers to support Indigenous people is needed. It may be helpful to provide Indigenous mentors for non-Indigenous staff who are inexperienced in working with Indigenous people. Recruitment and support for Indigenous volunteers and cancer survivors to assist in cancer advocacy work is in place in SA and Queensland, but not in other jurisdictions. One-to-one support services appear to be underutilised currently, and Indigenous-specific cancer survivor support resources using testimonials or story-telling may be helpful. An issue regularly raised within Indigenous cancer contexts was the use of traditional healers and traditional medicines,²² although

these issues were generally not mentioned by the informants interviewed. Support programs that integrate cultural components (traditional medicine, selected ceremonies) may be acceptable and effective means of supporting Indigenous people to engage in cancer treatment.

There are many similarities between the cancer issues experienced by Indigenous Australians and those of indigenous people in other developed countries. It is beyond the scope of this paper to discuss in detail the experience in cancer control and support strategies in indigenous populations in countries such as Canada, New Zealand and the United States. However, the authors have undertaken a comprehensive literature review of these populations and key lessons from international experience are: acknowledgement of past treatment and the impact of colonisation; acknowledgement of the cultural diversity of Aboriginal people; recognition of the impact of the structural causes of inequality; need to enable Indigenous ownership, participation, partnership and control, with Indigenous representation at all levels of decision making; and support for community-based and community-driven interventions. There have also been efforts to develop culturally appropriate resources and service-based programs, promoting Indigenous healing approaches concurrently with Western medical treatment. The reader is recommended to read further about these approaches²³⁻²⁸ which were generally Indigenous community-led and government supported.

While there has been a lack of Australian government leadership in this area, Cancer Councils can play both an effective practical and advocacy role at the local, state and national level to ensure Indigenous issues in cancer control are more effectively incorporated and heeded. Respondents recognised that this should be done “hand-in-hand in partnership with Indigenous communities”, and leadership is needed from The Cancer Council Australia to ensure that there is steady national progress with lessons shared across jurisdictions. The need for Cancer Councils to adopt a respectful approach that invests in learning and understanding about Indigenous

issues, and the reciprocal benefits that might derive from such partnerships in enhancing Indigenous cancer control are recognised in the words of one informant:

The Darwin Forum was like ... the Cancer Council people trying to learn from Aboriginal people ... and if we maintain that theme all the way through our state-based work or national work, we will do ok ... because we have developed lots of respect in taking that approach ...

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Competing interests

The authors declare that they have no competing interests.

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