

Identifying research priorities to improve cancer control for Indigenous Australians

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Key points

- Cancer prevention and early detection; health literacy; and culturally appropriate care for Indigenous patients, survivors and families are key research priorities to improve cancer control for Indigenous Australians
- Community engagement, Indigenous ownership, and partnership and collaboration are critical elements underpinning the research process
- These priorities will help to establish a research roadmap to reduce the burden of cancer for Indigenous Australians

Abstract

Objectives: The cancer burden is high among Australia's Indigenous population. Following a period of increasing attention by researchers, policy makers and consumers, this study aimed to identify emerging research priorities in Indigenous cancer control.

Methods: A survey was administered to a network of individuals with an interest in cancer and Indigenous Australians. Respondents ($N = 255$) described what they thought was the most significant research priority for cancer control for Indigenous Australians and ranked prespecified research areas relating to components of the cancer continuum.

Results: Identified research priorities included cancer prevention and early detection; health literacy; and culturally appropriate care for Indigenous patients, survivors and families. Community engagement, Indigenous ownership, and partnership and collaboration were highlighted as critical elements underpinning research.

Conclusions: The identified research priorities, along with seminal documents such as the National Aboriginal and Torres Strait Islander Cancer Framework, provide a roadmap for developing, funding, implementing and translating research to reduce the burden of cancer for Indigenous Australians.

Introduction

Cancer is the second leading cause of death among Aboriginal and Torres Strait Islander people (respectfully referred to as Indigenous Australians), and is responsible for more deaths each year than diabetes and kidney disease combined.¹ Indigenous Australians are more likely than other Australians to be diagnosed with rapidly fatal cancers (e.g. of the lung or liver) and less likely to be diagnosed with cancers that have better likelihood of survival (e.g. breast cancer or melanoma).^{2,3} In addition, many cancers that are amenable to prevention through reduced exposure to risk factors or early detection through screening programs are more common among Indigenous people.²⁻⁴ Among those diagnosed with cancer, Indigenous people are much

less likely to survive than non-Indigenous people (5-year survival 40% compared with 52%, respectively).²

Despite the substantial impact of cancer on Indigenous people, its importance has only begun to be recognised. In 2010, a Cancer Australia–commissioned review of cancer and Indigenous people provided a comprehensive summary of evidence and included 31 recommendations for improving Indigenous cancer control, including service delivery, data infrastructure, prevention and programs.⁵ This was followed in late 2010 by the National Roundtable on Priorities for Aboriginal and Torres Strait Islander Cancer Research.⁶ A key directive from this roundtable was for a national, coordinated, collaborative, priority-driven, Indigenous-led research effort to improve Indigenous cancer outcomes.⁶ Subsequently, the National Health and Medical Research Council (NHMRC) funded a Centre for Research Excellence (CRE) in Discovering Indigenous Strategies to Improve Cancer Outcomes Via Engagement, Research Translation and Training (DISCOVER-TT), and Cancer Council NSW funded a 5-year Strategic Research Partnership grant (STREP Ca-CInDA), with supplemental funding from Cancer Council Western Australia, to improve cancer control for Indigenous Australians.

Several initiatives have arisen from the DISCOVER-TT/STREP Ca-CInDA research program, including the creation of the National Indigenous Cancer Network (NICaN)⁷; the development of the first National Aboriginal and Torres Strait Islander Cancer Framework, on behalf of and in conjunction with Cancer Australia⁸; and hosting the inaugural World Indigenous Cancer Conference (WICC) in 2016, in partnership with the International Agency for Research on Cancer.⁹ Other Australian initiatives include the development of an integrated cancer monitoring and surveillance system to improve cancer care for Aboriginal people in South Australia, which has anticipated relevance for other regions¹⁰; the use of social inclusion theory to improve cancer care¹¹; and the assessment of patient navigator programs to improve diagnosis and treatment experiences.¹²

The capacity to monitor the health of Indigenous populations in Australia and other high-income countries is markedly hampered by the paucity of Indigenous identifiers in administrative datasets and cancer registries.¹³ However, evidence suggests that better health surveillance and targeted prevention, early detection, and vaccination programs are needed to reduce the higher rates of largely preventable cancers in Indigenous people in Australia, Canada, New Zealand and the US.¹³ In Canada, several studies have shown that cancer (of the cervix, colon and rectum, and breast) screening rates for Indigenous people are much lower than for non-Indigenous people.^{14–16} Research in New Zealand has looked at the role of cancer care in Indigenous cancer survival inequalities¹⁷, and called for the integration of cancer care across community-based cancer care, primary and secondary health care, and palliative care.^{18–20}

The research landscape in Indigenous cancer control has changed substantially since landmark work in 2010, and it is timely to reassess the research agenda. In this paper, we present the results of a process, using an online survey of individuals with an interest in this area, to identify emerging research priorities and refine the research agenda for Indigenous cancer control in Australia.

Methods

Ethical approval was obtained from the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC 2016-2671). An online survey with open- and closed-ended questions was developed, drawing on: 1) outcomes from the DISCOVER-TT/STREP Ca-CInDA research program, including annual research roundtables involving key stakeholders across Australia; 2) an environmental scan of international and national publicly available policies relating to cancer and Indigenous people; and 3) the WICC 2016 program. The recommendations and priorities identified from these sources (e.g. reports, publications, conference program themes) were synthesised to avoid repetition and categorised for inclusion in the survey into the following stages of the cancer continuum: prevention/early detection, diagnosis/treatment, supportive care/survivorship and palliative care.

The survey took approximately 15 minutes to complete, and asked participants to:

1. Nominate and describe the most significant research priority (a significant research knowledge gap or unmet need) they felt needed to be addressed in the area of cancer and Indigenous Australians (open-ended response)
2. Rank from predefined lists (prevention/early detection, diagnosis/treatment, supportive care/survivorship and palliative care) at least the top three research priorities within each list, with '1' being the highest ranking. Respondents were also given an opportunity at the end of each list to add any relevant priorities that were not included in the list. However, this did not yield any new information beyond that reported elsewhere in the survey.

An email invitation to participate and a link to the survey were sent to the registered WICC mailing list (including all conference delegates) and the large network of people known to the DISCOVER-TT/STREP Ca-CInDA team (including NICaN members). The survey invitation was limited to people residing in Australia. Participants included researchers, public health practitioners, clinicians, nurses, advocacy groups, allied health and other related professionals, Indigenous cancer survivors and their families, and Indigenous community groups. Reminder emails were sent 2 and 3 weeks after the initial email. The survey closed after 4 weeks. As stated on the online survey cover page, participants

provided informed consent by electing to take part in the survey.

Responses to open-ended questions were analysed using content analysis in NVivo qualitative data analysis software (QSR International version 11, 2015) and grouped into broad topic areas. The responses relating to each topic area were then reanalysed to gain a more nuanced interpretation of the topic as a research priority. Some priorities related to practice change or program implementation for improving service provision, which have been included here in recognition of the need to evaluate the efficacy and impact of a program. The ranked lists were assessed by calculating the percentage of respondents ranking an item as 1, 2 or 3, based on the total number of people who responded to that list. The synthesis of research priorities into a final list involved combining priorities that were common across both the qualitative responses and the top three ranked items from each section of the cancer continuum.

Results

Of 967 individuals and organisations invited to take part in the survey, 255 completed the survey (26% response rate). Of these respondents, 37% identified as being Aboriginal and/or Torres Strait Islander. Most respondents were female (79%) and aged between 45 and 54 years.

Most respondents lived in Queensland (30%) and New South Wales (25%); others lived in Victoria (15%), Western Australia (11%), South Australia (10%), the Northern Territory (7%), Tasmania (1%) and the Australian

Capital Territory (1%). The majority lived in metropolitan areas (capital city or major cities with population >100 000 people: 71%); others lived in rural centres (population 10 000–100 000: 20%), and other rural/remote locations (population <10 000: 9%). Many respondents were in a health professional role (46%) and/or a carer/family member of someone affected by cancer (33%) (Figure 1). Among the health professionals, prominent roles included nurse (17%), Indigenous health worker (13%) and health promotion/preventive care/healthy lifestyles worker (12%).

Most respondents were working in, or interested in all aspects of, the cancer continuum (49%), followed by prevention (38%), treatment (33%), screening and early detection (32%), survivorship and living well after cancer (26%), diagnosis (23%), and palliative care (18%).

Research priorities identified in open-ended questions

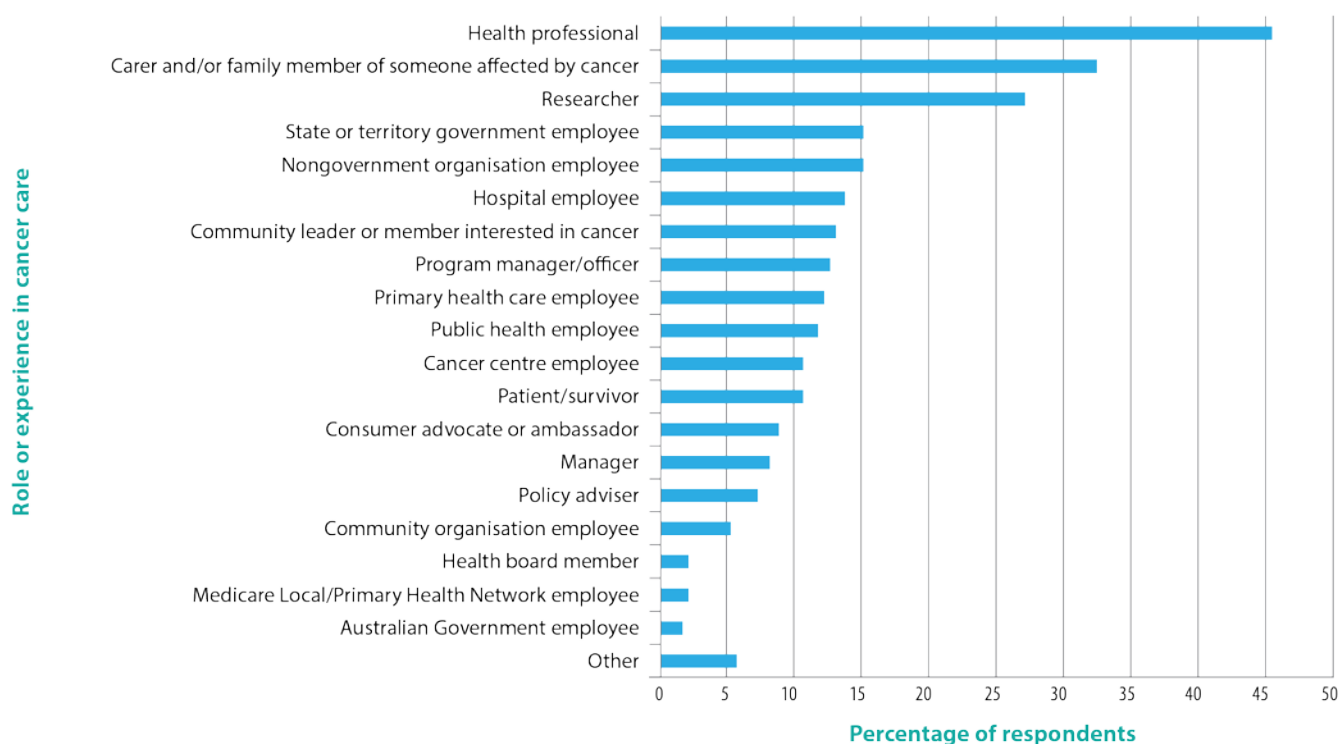
Content analysis of open-ended responses revealed that the 10 most commonly reported priorities could be grouped into the following three categories: cancer prevention and early detection, patient engagement with the system, and system-wide factors.

Cancer prevention and early detection

Prevention and healthy lifestyles

Cancer prevention was commonly cited as the most significant priority, with a focus on diet, smoking, alcohol and exercise. Social determinants of cancer were

Figure 1. Survey respondents' role(s) or experience in cancer care



Note: Responses were not mutually exclusive.

commonly cited, including intergenerational trauma and socio-economic disadvantage. Respondents reported that prevention strategies should target specific communities, use a lifecourse approach, involve community consultation and focus on primary health care.

Community education and health promotion

Many respondents called for research focusing on screening-related community education programs, community awareness about the link between lifestyle and cancer, and raising awareness of the benefits of early detection. An unwillingness to talk about cancer in Indigenous communities, together with shame and stigma associated with a cancer diagnosis, were identified as key issues. Respondents reported that education initiatives should be culturally appropriate, target youth and empower Indigenous communities.

Cancer screening

Screening was commonly reported as the foundation for reducing Indigenous cancer mortality. Improving data on Indigenous participation rates in screening programs was flagged, as was targeting underscreened and never-screened groups. Understanding the barriers to accessing and engaging in screening, and developing more proactive approaches were commonly cited, including outreach programs, community-based events, general health check-ups, and training for general practitioners and Indigenous health workers.

Timely diagnosis and early detection

The issue of timely diagnosis permeated respondents' comments across priorities and was identified as a critical goal of many other research priorities.

Engaging with the health system

Experience of care and system navigation

The inclusion of the views and experiences of Indigenous patients, families and the community in cancer research was commonly called for – specifically, approaches that are participatory, transformational and lead to rapid improvements in patient outcomes. Respondents identified the need to better understand patients' experiences of care, supportive requirements and cultural preferences to better facilitate patient-centred care.

Engagement with, and access to, services

Understanding the barriers and facilitators to Indigenous Australians' engagement with, and access to, health services was called for to improve screening rates, treatment efficacy and cancer outcomes. Issues identified as requiring research included health literacy, remote location, socio-economic disadvantage, cultural safety, language difference, impersonal approaches and fear.

Culturally appropriate services and educational materials

Respondents described the importance of developing culturally aware and responsive cancer services based on the needs, expectations and preferences of Indigenous patients. Systemic racism and poor understanding of Indigenous peoples' history and culture were highlighted as impediments to fostering culturally appropriate care.

System-wide factors

Indigenous workforce

Increasing the number of Indigenous people working in all areas of the health system was widely mentioned. The need to improve support, education and opportunities for Indigenous people in the health workforce was identified as key to creating culturally appropriate services, and fostering effective and positive engagement with patients.

Remote community issues

The compounding disadvantages experienced by Indigenous Australians in remote areas was interwoven throughout the respondents' comments. The pressing need for high-quality cancer services in regional and remote areas was made clear, including increased cancer-specific training for remote health providers, greater incentives to retain local staff, greater coverage of cancer outreach services, and improved access to technology and diagnostic facilities. Several respondents reported that Indigenous Australians living in remote areas face substantive barriers to engaging with urban-based cancer services, including financial and logistical difficulties of travel, accommodation and childcare; cultural and language differences; lack of family and community support; and a widespread lack of understanding of these challenges by non-Indigenous care providers. Researching the challenges facing remote Indigenous peoples with cancer was described as important in achieving equity in access to care.

Community engagement and self-determination

Increasing Indigenous involvement and data sovereignty in cancer research was described as critical to ensuring that Indigenous values and priorities underpin research. A greater focus on community education, face-to-face consultation and inclusion of community members in clinical, policy and research leadership were identified as essential steps towards servicing the needs of Indigenous Australians more effectively and in reducing cancer disparity.

Ranked research priorities across the cancer continuum

Respondents' rankings on the four prespecified lists were largely consistent with the open-ended responses relating to research priorities. Research priorities are presented in ranked order for each list in Table 1a–d.

Table 1. Ranked research priorities for Indigenous cancer control across the cancer continuum

a Prevention and early detection (<i>n</i> = 182)				
Rank	Priority	<i>n</i>	% ^a	
1	Develop and evaluate programs that increase awareness and understanding of preventable cancer risks (e.g. tobacco smoking, unhealthy weight, hazardous alcohol consumption, sedentary lifestyle, poor nutrition)	79	43.4	
2	Identify the barriers and enablers to participation in cancer screening for Indigenous people	60	33.0	
3	Identify ways to improve cancer health literacy in the workforce and community	56	30.8	
4	Identify how to overcome these barriers and increase screening rates through culturally appropriate outreach efforts	54	29.7	
5	Identify the best ways to improve Indigenous people's awareness of early signs and symptoms of cancers	52	28.6	
5	Identify specific barriers and enablers to minimise cancer risk for Indigenous people	52	28.6	
6	Identify ways that the health workforce can engage communities in early screening and detection initiatives	36	19.8	
7	Understand stigma and shame regarding cancer and screening for cancer, and ways to overcome this	30	16.5	
8	Identify the best ways to follow up on early signs and symptoms of cancers	28	15.4	
9	Identify best-practice models of delivery of cancer screening programs	25	13.7	
10	Research hereditary links, change of diet, environmental pollutants, and their impact on cancer rates in Indigenous people	22	12.1	
11	Improve knowledge/understanding of known environmental risk factors	14	7.7	
12	Find local explanations for why particular cancers are of concern in particular areas	13	7.1	
13	Identify barriers and enablers to maximise vaccination uptake	9	5.0	

^a Percentage of respondents who ranked the item as 1, 2 or 3.

b Diagnosis and treatment (<i>n</i> = 167)				
Rank	Priority	<i>n</i>	% ^a	
1	Identify new models of care to meet the needs of rural and remote Indigenous communities, to improve access to programs and services	89	53.3	
1	Identify how to improve the acceptability and accessibility of health services and their responsiveness to the needs of Indigenous people	89	53.3	
2	Develop, implement and evaluate culturally responsive resources	59	35.3	
3	Develop, implement and evaluate culturally appropriate patient navigation	53	31.7	
4	Identify the best approaches to facilitate and sustain Indigenous ownership and involvement in all aspects of service delivery	52	31.1	
5	Identify new models of care to meet the needs of Indigenous people in metropolitan areas, to improve access to programs and services	47	28.1	
6	Understand the impact of complex health needs, including high rates of comorbidities	38	22.8	
7	Assess ways to improve capacity to identify Indigenous cancer patients correctly	23	13.8	
8	Identify optimal ways to assess and manage supportive care needs	22	13.2	
9	Improve measurement of patient experience and outcomes	21	12.6	
10	Identify optimal ways to assess and manage clinical needs	17	10.2	

^a Percentage of respondents who ranked the item as 1, 2 or 3.

continued

Table 1. Ranked research priorities for Indigenous cancer control across the cancer continuum (*continued*)

c Supportive care and survivorship (*n* = 165)

Rank	Priority	<i>n</i>	% ^a
1	Identify physical, mental, spiritual, practical and financial needs of patients and their families, and ensure access to programs and services that address these needs	114	69.1
2	Identify optimal ways to provide supportive care beyond treatment completion	83	50.3
3	Develop greater understanding of the needs of other people involved in an Indigenous patient's cancer journey (e.g. carers)	65	39.4
4	Develop, implement and evaluate patient navigation programs for cancer survivors	63	38.2
5	Pilot innovative transition services for patients with cancer between cancer care centres and home	60	36.4
6	Understand ways to involve and inform families and carers of Indigenous people with cancer	49	29.7
7	Understand ways in which peer support can help Indigenous cancer survivors	41	24.9

^a Percentage of respondents who ranked the item as 1, 2 or 3.

d Palliative care (*n* = 159)

Rank	Priority	<i>n</i>	% ^a
1	Increase understanding of, and address barriers to, access and use of palliative care services by Indigenous people	123	77.4
2	Identify best ways to deliver culturally appropriate palliative care	116	73.0
2	Identify the palliative care needs of Indigenous cancer patients and their families	116	73.0
3	Develop and evaluate training models for clinicians to be trained in end-of-life care and palliation	54	34.0
4	Identify effective referral pathways for palliative care	51	32.1

^a Percentage of respondents who ranked the item as 1, 2 or 3.

Synthesised list of research priorities

The key research priority areas for improving cancer control for Indigenous Australians are summarised in Box 1.

Discussion

The research priority areas identified in this project advocate focus in the areas of cancer prevention and early detection; health literacy; and provision of culturally appropriate care for patients, survivors and families. Underpinning this research are critical elements of meaningful community engagement, Indigenous ownership, and working in partnership and collaboration to reduce the burden of cancer on Indigenous Australians. We recognise that some priorities relate to changes that could be made in the short term based on existing knowledge. However, these are included as research priorities in recognition of the importance of evaluating the barriers and facilitators to successful implementation, and assessing the effectiveness and impact of such changes in real-world settings.

The priorities identified in this project are broadly consistent with the priority areas for action in the National Aboriginal and Torres Strait Islander Cancer Framework.⁸ The identified research priorities are particularly consistent with framework priorities 1 (improving knowledge, attitudes and understanding), 5 (optimal and culturally appropriate treatment, support and care) and 7 (strengthening capacity of health services). The results of this project provide a way forward for “targeted and priority research to inform policy, health promotion, service provision and practice” (framework priority 7b).

As was the case with the development of the Framework, the research priorities identified in this project were developed through the involvement of key stakeholders, including a broad range of researchers, public health practitioners, clinicians, nurses, advocacy groups, allied health and other related professionals, Indigenous cancer survivors and their families, and Indigenous community groups. These comprehensive findings represent a broad consensus of key people involved in cancer control for Indigenous people.

As a result of the recent increase in attention on Indigenous cancer control, there is now greater awareness among policy makers, health service

Box 1. Summary of research priorities for improving cancer control for Indigenous Australians

Cancer prevention and early detection

- Develop and evaluate ways to increase awareness and understanding of cancer risks, symptoms and cancer screening
- Understand the barriers and enablers to participation in cancer screening programs
- Develop, implement and evaluate evidence based strategies to increase participation in cancer screening

Health literacy

- Identify ways to improve cancer health literacy in the health workforce and community
- Develop, implement and evaluate culturally responsive resources

Culturally appropriate care for cancer survivors and their carers/family

- Implement and evaluate culturally appropriate outreach efforts and health services (at a system-wide level rather than individual services)
- Identify new models of care for Indigenous people in rural, remote and metropolitan areas
- Assess the acceptability and accessibility of health services and their responsiveness to needs
- Identify barriers and enablers to accessing and completing treatment
- Identify unmet needs (e.g. physical, spiritual, financial, practical) and ensure that programs and services are in place to meet those needs
- Develop, implement and evaluate patient navigation programs
- Investigate ways to improve survivorship care (i.e. beyond treatment completion)
- Identify the needs of carers and develop ways to support the family
- Understand palliative care needs and identify barriers to accessing palliative services for families and patients

Cross-cutting themes

- The need to establish partnerships and to collaborate with key stakeholders
- Community engagement and Indigenous ownership in all aspects of the research process

providers, and Indigenous leaders and communities, as well as a more active research effort across several research groups. However, much research remains to be done across the cancer continuum to improve cancer outcomes for Indigenous Australians.

Limitations of the project include the low response rate (26%) and the inability to determine whether the respondents were representative of the larger database of people invited to participate, because of the lack of demographic information in the database. However, a significant proportion of the respondents identified as Indigenous, were geographically diverse, and represented a variety of occupations and consumer groups.

The identified list of current research priorities, along with seminal documents such as the National Aboriginal and Torres Strait Islander Cancer Framework⁸, provide a useful roadmap to guide the development, funding, implementation and translation of research and service development to reduce the burden of cancer for Indigenous Australians. This roadmap can be used by researchers, policy makers and service providers to focus on key areas to improve cancer control for Indigenous people. Funding bodies can also use the priority actions from the framework and the priority research areas identified in this project to focus future research.

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Competing interests

None declared

Author contributions

BM led the study, conducted the quantitative analysis and drafted the manuscript. KA conducted the qualitative analysis, drafted the qualitative results and contributed to the manuscript. JC and GG provided guidance for the study and data analysis, and contributed to writing and editing the manuscript.

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