Action on Indigenous cancer research priorities: Report from NICaN 2013 Roundtable

The National Indigenous Cancer Network (NICaN) is a national network that aims to encourage and support collaboration around cancer research and services for Aboriginal and Torres Strait Islander people with cancer, their carers and families. It is supported by a partnership between Menzies School of Health Research, Australian Indigenous Health*InfoNet*, Cancer Council Australia and The Lowitja Institute.

The 2013 Roundtable

In March 2013 a two-day National Indigenous Cancer Network (NICaN) Roundtable was held which focused on engagement, research translation and training; using strategies for connecting, communicating and collaborating. The roundtable was attended by more than 80 people representing 47 different organisations over a range of sectors, services and research groups involved in cancer work with Aboriginal and Torres Strait Islander people.

Research gaps and areas for action

One of the main aims of the roundtable was to review current research and translation priorities. Professor Joan Cunningham reported on progress in addressing research gaps or issues identified in Cancer Australia's 2010 review of Aboriginal and Torres Strait Islander cancer control[1], and the Lowitja Institute's National Roundtable on Aboriginal and Torres Strait Islander Cancer Research[2]. Groups of participants discussed how to move forward on key priority areas of: data collection and management; service delivery and models of care for diagnosis, treatment and care; workforce development and education; communication; consumer advocacy and support; and prevention. Feedback about each priority area is reported below. It is intended this report will provide guidance for researchers, research partnerships, students and research funders in considering priority areas for investment and effort in Aboriginal and Torres Strait Islander cancer research.

Common themes

Several common themes emerged across the priority areas, including:

- don't duplicate research activities – it is important to share findings and build on what is already happening

- evaluation is key – it is important to demonstrate impact (or lack thereof).

- ensuring appropriate and effective communication between health care providers and Aboriginal and Torres Strait Islander people about cancer is critical to achieving improvements across the spectrum of cancer services

- the 2010 Cancer Australia report continues to provide a good basis for priority setting.

Priority areas

Data collection and management

Key issues/gaps included:

- under-identification of Aboriginal and Torres Strait Islander people in key datasets that feed into cancer registries, including primary care, pathology reports and hospital data

- issues with cancer registry data in addition to under-identification, such as lack of staging information and data not being kept up-to-date

- uncertainties surrounding clinical cancer registries, including sustainability, Indigenous identification and details about treatment

- the need to ensure governments and practitioners are aware of research and findings, and the challenge of embedding research innovation into routine monitoring of health systems

- difficulties accessing cause-of-death data from the Australian Bureau of Statistics

- the need for more information on nursing care and non-Medicare Benefits Schedule (MBS) services

- the importance of functional and sustainable data linkage units covering all jurisdictions.

There was also agreement with the recommendations in the 2010 Cancer Australia report to:

- address under-identification of Aboriginal and Torres Strait Islander status in registries and administrative databases, including clinical registries and pathology reporting, which is central to data monitoring issues

- close data gaps through linkages, including between registry and administrative databases to assess the effects of early diagnosis initiatives at a primary care level It will also be important to demonstrate the value of data linkages to government

- address gaps in data – in particular, data on the stage and spread of disease, and cause of death

- improve data about participation in cervical cancer screening within Aboriginal and Torres Strait Islander communities

- ensure that monitoring occurs at a national level across the care continuum, and that there are feedback loops between monitoring and research.

Service delivery and models of care: Diagnosis

Key problems in diagnosis include late diagnosis; late presentation; presence of multiple symptoms and co-morbidities; choice and accessibility of services; and referral protocols. Key research gaps relate to timeliness of diagnosis; time from diagnosis to referral, and from diagnosis to treatment; urban–rural disparities; and economic benefits of early diagnosis.

Key research questions in the area of diagnosis might include:

- what is the journey to diagnosis?

- where are the incremental differences in time/process along the diagnostic pathway for people from Aboriginal and Torres Strait Islander communities vs. non-Indigenous Australians, given that incremental differences may combine to produce significant differences in outcomes

- how can a diagnosis of cancer be effectively communicated to people from Aboriginal and Torres Strait Islander communities? This incorporates clarifying the diagnosis process, including any tests involved, and what the diagnosis means. What information might patients and families need to understand and deal with the diagnosis, and how might that information be communicated in a culturally appropriate way?

- what are the economic – as well as social and health – benefits of early diagnosis?

Service delivery and models of care: Treatment and care

Key issues/gaps included:

- failure to take up and/or complete treatment

- failure to meet the needs of patients at entry in to treatment

- barriers to access to treatment, including geographic, cultural, financial, social and family responsibilities

- education of both patients and providers, and the effectiveness of communication between providers and patients and their families. There are two main areas of need from a patient education perspective: 1) what the diagnosis actually means; and 2) the importance of treatment. Education (for both health professionals and patients) will be key to improving models of treatment and care.

- The need for evaluation (as well as long-term funding) for promising pilot programs. Care coordination (through patient navigators for example) and integrated, holistic care have great potential for improving treatment and care for Indigenous cancer patients, but must be underpinned by rigorous evaluation.

Workforce development and education

Key gaps/issues included:

- Health literacy and good practice in communication by health practitioners: A need for basic information, using multiple approaches to achieve effective communication. Challenges include lack of resources, lack of access, workforce instability, lack of training pathways, lack of information in specific languages, and lack of recognition and respect for Aboriginal and Torres Strait Islander health care workers. It is also necessary to educate all health professionals about culturally appropriate and transparent communication using lay terms, not medical jargon.

- A lack of Aboriginal and Torres Strait Islander 'faces' in the patient journey. It is important to involve Aboriginal Health Workers (AHWs) and Indigenous Liaison Officers (ILOs) as part of the patient journey, and that there is mainstream recognition of the critical contribution of these staff. Clinical supervision and self-care strategies will be important to ensure AHW's and ILOs are not overburdened. AHWs and ILOs need to understand cancer care and the needs of patients with cancer, and resources required to support this learning.

Research gaps identified included:

- understanding how to address taboos about cancer in communities (with a recognition that this will vary by community)

- comparing patients' experiences with or without the availability of an Aboriginal or Torres Strait Islander health care worker

- understanding what models of care work best for people from Aboriginal and Torres Strait Islander communities.

In developing educational resources and programs, it would be helpful to identify what AHWs know about cancer. When considering training models, it would be good to provide a model for training that is dependent on the level of specialisation required – i.e. what do all AHWs need to know vs. what do people in oncology-specific roles need to know?

Communication

Communication between health professionals and patients and families is key to addressing disparities. The focus of this communication should be on achieving the best possible outcome for patients. This will require the presentation of both basic information and more specific, in-depth information, and a different suite of tools may be required for each level. It is critical to build evidence and share evidence **at** all levels **for** all levels. It was recognised that there is no one solution – multiple approaches and flexibility will be required.

Potential research gaps include:

- lots of published and disseminated materials have been developed (e.g. posters and brochures), but what information do consumers actually prefer and how can they access it?

- what is 'best practice' in communicating about cancer for Aboriginal and Torres Strait Islander people? What has been effective, and in what circumstances? How can 'best practice' incorporate flexibility and responsiveness to the information needs of diverse individuals, at different points in the patient journey?

- who is accessing on-line health information and how is it being used?

- what effect is telemedicine having on the nature of communication between health professionals and patients and families?

- how should support personnel be effectively integrated into the interactions between patients and care providers?

- how can cultural training be used to improve the effectiveness of communication about cancer?

Consumer advocacy and support

Key issues/gaps identified included:

- exploring ways to increase the uptake of cancer screening programs by Aboriginal and Torres Strait Islander people

- importance of health services providing culturally appropriate coordination of care

- the importance of channels through which Aboriginal and Torres Strait Islander cancer patients can be heard

- provision of support for people travelling long distances for treatment – not just to airports but from airports to health services; the need for culturally appropriate accommodation and support for people away from home for treatment

- encouraging Aboriginal and Torres Strait Islander people who have experienced cancer to become advocates for their mob

- importance of transparency and clear communication in discussions about diagnosis and treatment to ensure key information is understood

- exploration of how to foster trust in health services

- consideration of both the patient's and community's needs

- evaluation of what has worked previously.

The group discussed a range of approaches to communication of information, including:

- agreement on appropriate language/lay terms

- use of music, drama, pictures and interactive cartoons as part of communication of key messages

- use of appropriate channels for communication of information – such as local radio, festivals, presentations to youth groups

Prevention

Many of the key messages that relate to prevention and early detection also apply to post-treatment/survivorship and general chronic disease management. The approach to patients must be culturally competent and de-bunk existing myths about cancer.

Potential research gaps include understanding the effects of co-morbidities on cancer outcomes; identifying the right communication 'technologies' to deliver effective messages; how best to use community leaders/champions; and how can diagnosis be improved in regional/remote Australia, including through the use of new technology.

Conclusion

It is intended this report will provide guidance for researchers, research partnerships, students and research funders in considering priority areas for investment and effort in Aboriginal and Torres Strait Islander cancer research. The priorities and strategies presented here build on and should be read in conjunction with those identified in the Cancer Australia 2010 review of Aboriginal and Torres Strait Islander cancer control[1], and the Lowitja Institute's National Roundtable on Aboriginal and Torres Strait Islander Cancer Research[2].

Cancer outcomes for non-Indigenous Australians have dramatically changed over recent years, primarily through improved diagnosis and treatment, and through preventive measures such as tobacco control. Similar improvements in outcomes are achievable for Aboriginal and Torres Strait Islander Australians. If you are already doing research in this area, or are interested in contributing to this important work through research, please visit the NICaN website at www.nican.org.au; email nican@menzies.edu.au, or Tweet @NICaN_Australia.

References

1. Miller J, Knott V, Wilson C, Cunningham J, Condon J, Roder D, et al. Aboriginal and Torres Strait Islander Cancer Control Research Project. Commissioned report to Cancer Australia, July 2010. Available at: http://canceraustralia.gov.au/publications-resources/cancer-australia-publications/aboriginal-and-torres-strait-islander-cancer.
2. Garvey G, Cunningham J, Valery PC, Condon J, Roder D, Bailie R, Martin J & Olver I. 2011. Reducing the burden of cancer for Aboriginal and Torres Strait Islander Australians: time for a coordinated, collaborative, priority-driven, Indigenous-led research program, Medical Journal of Australia, 194 (10): 530-531.