

SHAPING THE FUTURE

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Indigenous people and cancer



The Centre of Research Excellence in Discovering Indigenous Strategies to improve Cancer Outcomes Via Engagement, Research Translation and Training (DISCOVER-TT CRE) was funded by the National Health and Medical Research Council (#1041111), and the Strategic Research Partnership to improve Cancer control for Indigenous Australians (STREP Ca-CIndA), was funded through Cancer Council NSW (SRP 13-01) with supplementary funding from Cancer Council WA. We also acknowledge the ongoing support of the Lowitja Institute, Australia's National Institute for Aboriginal and Torres Strait Islander Health Research.

We thank the DISCOVER-TT Advisory Board, and Chair Alwin Chong, for their great efforts and contribution to this program of research.

DISCOVER-TT and STREP CaCIndA partners and collaborators.



Throughout this document, we respectfully refer to Australia's Aboriginal and Torres Strait Islander people as Indigenous.

REFERENCES

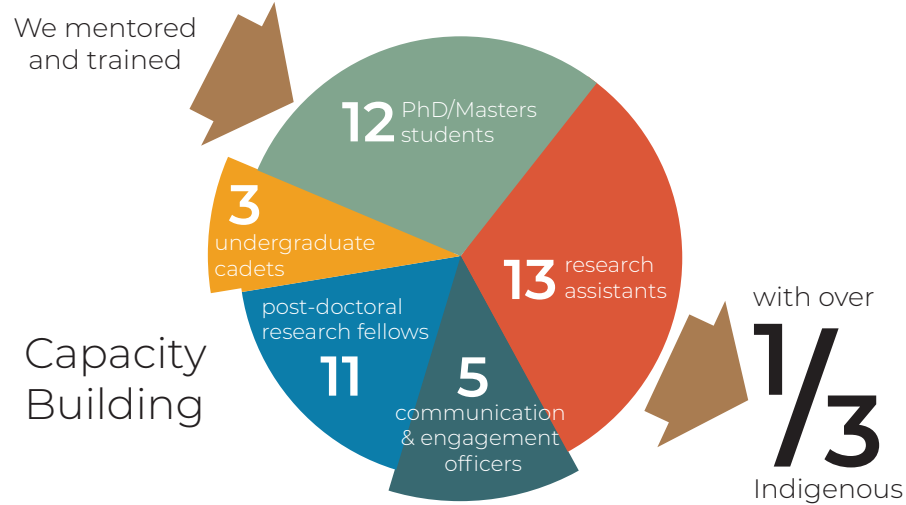
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2. Menzies School of Health Research, 2016. Report to the Australian Government Department of Health, unpublished.
3. Whop LJ, Garvey G, Baade P, et al. The first comprehensive report on Indigenous Australian women's inequalities in cervical screening: A retrospective registry cohort study in Queensland, Australia (2000-2011). *Cancer* 2016; 122(10): 1560-9.

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DISCOVER-TT and STREP CaIndA: what we have achieved

The Centre for Research Excellence (NHMRC funded), in Discovering Indigenous Strategies to Improve Cancer Outcomes Via Engagement, Research Translation and Training (DISCOVER-TT) was established in 2013. Additional funding was obtained later that year from a Strategic Research Partnership with Cancer Council NSW (STREP CaIndA). At that stage, relatively little was known about the needs of Indigenous cancer patients and their families. DISCOVER-TT and STREP aimed to address these knowledge gaps and bring together key researchers, health professionals and consumer advocacy groups from across Australia. This brochure outlines some of the major achievements that have been made under this research program since 2013.



Competitive Funding

We have been successful in gaining substantial additional competitive funding

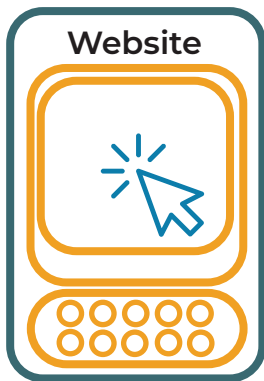


Conference Presentations

73 presentations – 18 international and 55 national presentations

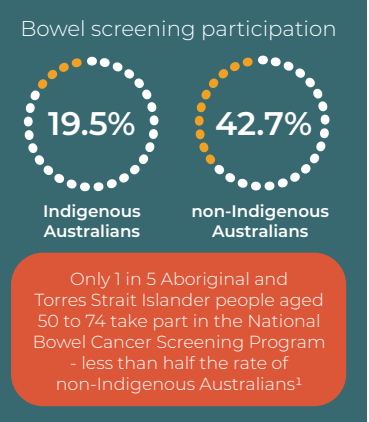
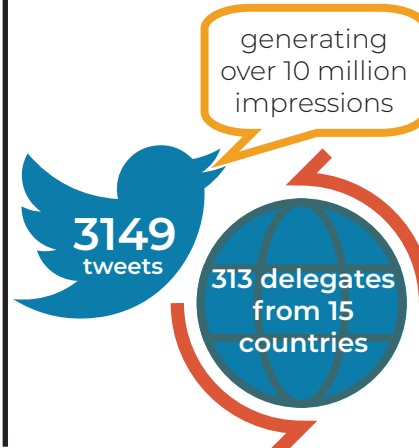
35 publications from 2014 to 2018, with many more still to be published. These publications reflect the broad range of areas covered in the research program, including: screening; comorbidities; supportive care; palliative care; traditional and complementary medicine; out-of-pocket costs; service innovation, epidemiology; research priorities and much more.

The **National Indigenous Cancer Network (NICaN)** was established to improve outcomes for Indigenous people with cancer, including their carers, families and communities. NICaN brings together Indigenous audiences, cancer survivors, service providers, researchers and health professionals from a broad range of disciplines, as well as private sector, government, and NGO organisations. Through NICaN we can support Ambassadors, who are cancer survivors and carers, sharing their stories and helping others understand cancer and the importance of screening. www.nican.info



The **World Indigenous Cancer Conference** in 2016 was the first conference focusing on cancer among Indigenous populations globally.

The presentations reflected the broad range of delegates' experiences and backgrounds. An important part of the program was the Yarning Circle dedicated to First Nations people sharing their stories. www.wicnetwork.org



Bowel Screening

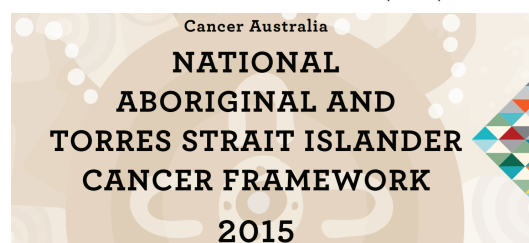
The National Indigenous Bowel Screening Pilot hopes to make bowel screening more accessible for Indigenous Australians and improve screening rates. Consultations in 2015-16 found many of the barriers to participation could be addressed if eligible Indigenous people received the screening kit directly from a trusted health professional at their local health care service². To address these barriers the Pilot involves around 50 primary health care centres handing bowel screening kits directly to patients. www.indigenousbowelscreen.com.au

Supportive Care Needs

A culturally appropriate tool was developed to assess supportive care needs of Indigenous cancer patients. This tool was found to be acceptable to patients and clinical staff and training significantly increased the confidence and knowledge of staff. This tool is currently being implemented into routine care around Australia. We are now developing a tool to assess the unmet needs of caregivers of Indigenous cancer patients.

Cancer Framework

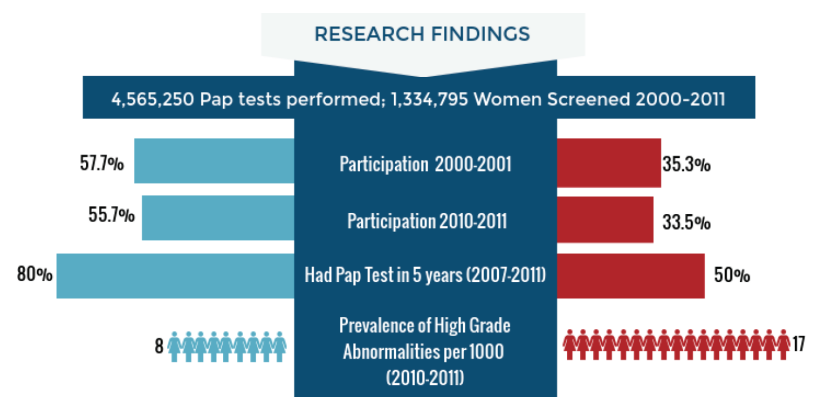
Menzies, in conjunction with Cancer Australia, developed the National Aboriginal and Torres Strait Islander Cancer Framework. The Framework provides high-level guidance and direction for the many individuals, communities, organisations and governments working to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples.



Cervical Screening

Whop et. al. found Indigenous women participate less in cervical screening compared to non-Indigenous women (Qld data) as shown below³.

Positive findings showed that for the third of Indigenous women that did participate in screening, most had a history of screening previously (meaning that once you are on board with screening, you keep going). To work towards closing the participation gap, we are now conducting the Screening Matters study to better understand the views of women who both do and don't screen.



THE FUTURE: TACTICS 2019-2023

New NHMRC funded "TACTICS" CRE – Targeted Approaches To Improve Cancer Services for Aboriginal and Torres Strait Islander Australians.

This new program of work aims to:

- ✓ increase cancer prevention and early detection through immunisation and screening;
- ✓ improve diagnosis and treatment through health service innovation; and
- ✓ provide appropriate care to enhance psychosocial wellbeing of Indigenous cancer survivors, their partners and carers across the cancer continuum.

TACTICS is an Indigenous-led research program with collaborations between Menzies School of Health Research, Victorian Cytology Service, Uni of NSW, Uni of SA, Uni of Sydney, Genesis Cancer Care, James Cook Uni, Cancer Council Qld, and Wuchopperen Health Service. This CRE will actively promote the translation of research knowledge into public health policy and practice, and also continue to build research capacity through training the next generation of researchers in Indigenous cancer control.

Whisper No More Sharing our stories for better cancer outcomes

Thompson et al have developed an online curriculum training package for health science students and health care professionals that explores themes of culturally safe practice, clinical yarning and communication, community education about prevention and overcoming delays in diagnosis, support systems and the importance of family. Narratives are incorporated into the training, empowering Indigenous people to actively seek medical advice, to question, to ask for second opinions and to listen to their own bodies. Feedback from medical students revealed their heightened awareness of early detection and diagnosis and effective communication skills particularly around end-of-life wishes.