SHAPING THE FUTURE
Indigenous people and cancer

Roundtable
11-12th September 2018
Darling Harbour, Sydney
Contents

1. Introduction .................................................................................................................................................. 4
2. Delegates ...................................................................................................................................................... 5
3. Roundtable Agenda .................................................................................................................................. 5
3.1. Mapping the Landscape ....................................................................................................................... 6
3.2. Panel Discussions ................................................................................................................................... 7
3.2.1 Cancer Prevention and Early Detection .............................................................................................. 7
3.2.2 Culturally appropriate cancer care – with a focus on diagnosis and treatment ............................... 7
3.2.3 Palliative care, End of Life care, and Families and Carers ................................................................. 9
3.2.4 Survivorship and Advocacy ............................................................................................................... 10
3.3. Identifying priorities for cancer control for Aboriginal and Torres Strait Islander people ................ 11
3.4. Visions and action planning in cancer control for Aboriginal and Torres Strait Islander people ........ 12
3.4.1. A changed narrative around cancer .................................................................................................. 12
3.4.2. An appropriate workforce across the cancer control spectrum .................................................... 13
3.4.3. Cancer Prevention – focussing on tobacco use ............................................................................... 13
3.4.4. Cancer Prevention and Early Detection – screening and immunisation ....................................... 14
3.4.5. Indigenous cancer care teams .......................................................................................................... 16
3.4.6. Cancer Care adhering to Optimal Care Pathways (OCP) ................................................................. 16
3.4.7. Survivorship ...................................................................................................................................... 17
3.4.8. Palliative and End of Life Care ........................................................................................................ 18
4. Summary and conclusions ............................................................................................................................. 19
5. Appendices .................................................................................................................................................. 19
   Appendix 5.1: Discover-TT and STREP CaClndA overview .................................................................... 20
   Appendix 5.2: List of Roundtable Attendees ............................................................................................ 21
   Appendix 5.3: Roundtable Agenda ........................................................................................................... 23
   Appendix 5.4: Day 1 & 2 Worksheets ........................................................................................................ 24
1. Introduction

Shaping the Future Roundtable: Indigenous people and Cancer

The Shaping the Future: Indigenous People and Cancer Roundtable, held in Sydney on 11-12th September 2018, was an initiative of Menzies School of Health Research (Menzies). Research Roundtables are an important part of Menzies’ approach to research. The two-day program gave stakeholders the opportunity to pause, consider what has been achieved over the last decade, and discuss where research can have the most impact on improving cancer outcomes for Aboriginal and Torres Strait Islander people.

We employed Futures Planning to consider the issues and trends visible in the current landscape, and how these might influence the future of Aboriginal and Torres Strait Islander people with respect to cancer. Considering these influences and trends, we envisaged a future that best supports Aboriginal and Torres Strait Islander people affected by cancer.

Where we started...

Early in 2010, Cancer Australia commissioned a review to provide a comprehensive summary of evidence regarding cancer and Aboriginal and Torres Strait Islander people. This review included 31 recommendations for improving cancer control for Aboriginal and Torres Strait Islander people, including service delivery, data infrastructure, prevention and programs. Later that year a National Roundtable on Priorities for Aboriginal and Torres Strait Islander Cancer Research, funded by Lowitja Institute, was held. This Roundtable brought together leading cancer experts, Aboriginal and Torres Strait Islander people cancer survivors and community representatives, with an aim to identify national research priorities to achieve better outcomes for Aboriginal and Torres Strait Islander people with cancer, their families and communities.

A key directive from this roundtable was for a national, coordinated, collaborative, priority-driven, Indigenous-led research effort to improve cancer outcomes for Aboriginal and Torres Strait Islander people; which led to the NHMRC-funded Centre for Research Excellence in Discovering Indigenous Strategies to Improve Cancer Outcomes Via Engagement, Research Translation and Training (DISCOVER-TT) being established in 2013. Additional funding was obtained later that year from a Strategic Research Partnership with Cancer Council NSW (STREP CaCIndA), with supplemental funding from Cancer Council WA. The aims of these research programs for Aboriginal and Torres Strait Islander people affected by cancer focussed on the pathways and outcomes of care and improving models of care and service delivery.

Since 2013, a number of key outcomes have been achieved by the team at Menzies and their DISCOVER-TT CRE collaborators, such as: the National Indigenous Cancer Network (NICaN), including supporting Aboriginal and Torres Strait Islander Cancer Ambassadors; developing the first National Aboriginal and Torres Strait Islander Cancer Framework, on behalf of and in conjunction with Cancer Australia; hosting the inaugural World Indigenous Cancer Conference in 2016, in partnership with the International Agency for Research on Cancer; developing and implementing a culturally appropriate tool to identify and address the unmet supportive care needs of Aboriginal and Torres Strait Islander cancer patients in clinical practice; and the first population-based comprehensive report on Aboriginal and Torres Strait Islander participation in cervical screening (see Appendix 5.1 for some of the highlights of the DISCOVER-TT CRE). This research program has continued into 2019 with the NHMRC funded CRE Targeted Approaches to Improve Cancer.
Services (TACTICS) for Aboriginal and Torres Strait Islander people, with a focus on emerging priorities in cancer-related health services research.

Other initiatives have occurred and are continuing across Australia, these have included 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 regions\(^1\); improving cancer care through social inclusion theory\(^2\); improving diagnosis and treatment experiences through patient navigator programs\(^3\); and many others.

The landscape in cancer control for Aboriginal and Torres Strait Islander people has changed substantially since the landmark review in 2010, and subsequent development of a Cancer Framework and Optimal Care Pathways. It is now time to reassess the research agenda.

Where we are heading...

The *Shaping the Future: Indigenous People and Cancer* Roundtable brought together key stakeholders to imagine what the future looks like for Aboriginal and Torres Strait Islander people. The aim of the Roundtable was to identify priorities for future practice, policy, and research and begin to develop actionable plans needed to create and shape the desired future.

2. Delegates

In order to consider the emerging trends relevant to cancer outcomes for Aboriginal and Torres Strait Islander people in Australia and how to create a strong future, we involved Aboriginal and Torres Strait Islander people affected by cancer and key people working in research, policy and clinical practice in the Roundtable. These included 52 people from across Australia; with representatives from cancer control organisations, government, researchers, health professionals, Aboriginal and Torres Strait Islander people affected by cancer, and Aboriginal Community Controlled Organisations (see Appendix 5.2 for a list of attendees).

3. Roundtable Agenda

The two-day program (see Appendix 5.3 for Roundtable agenda) commenced with a Welcome to Country by Gadigal Elder Uncle Charles (Chicka) Madden. Roundtable delegates were given the opportunity to cleanse the past for a better future through a smoking ceremony and welcome dance performed by Gumaroy.

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The Roundtable was facilitated by Dhinawan (Mick Baker), who is a descendant of Gamilaroi Bigambul tribe and founder of Dhinawan Dreaming. The opening address, by Gail Garvey from Menzies, presented our shared history, the current landscape, and why we were gathered at the Roundtable.

3.1. Mapping the Landscape

To introduce the concepts of Futures Planning, Jenny Brands from Menzies, outlined how delegates were going to map the landscape and imagine a future in 2030 (pointing out that it was only as far away as 2006!). Initial exercises involved groups of delegates identifying emerging trends that may impact on an imagined future for Aboriginal and Torres Strait Islander people and cancer (see Figure 1). For example, some emerging factors that may impact on cancer outcomes could include e-health, the health of the planet, immunisation (e.g., HPV), globalisation, ageing population, social media, constitutional reform, and loss of language – just to name a few.

The emerging trends that can impact on cancer control leading up to 2030 were reported by delegate groups and centred around four key themes, including:

- Workforce (e.g., Aboriginal and Torres Strait Islander staff, training, long-term funding)
- Service delivery (e.g., personalised medicine, continuity of care, multidisciplinary care, screening and prevention, holistic and culturally appropriate care including a recognition of the role that Country has on health and healing)
- Technology (e.g., genomics, telemedicine, e-records, data integrity and governance)
- Context (e.g., constitutional recognition/treaty, racism, social determinants of health, ageing population, caring for carers, increasing costs of health, multiple chronic conditions)

The potential impact from these trends were considered throughout the Roundtable when discussing future scenarios and developing action plans to achieve imagined outcomes.
3.2. Panel Discussions

Four panel discussions provided delegates with an overview of the current landscape and where we are headed in cancer care and control for Aboriginal and Torres Strait Islander people across the cancer continuum: Cancer Prevention and Early Detection; Culturally Appropriate Care – Focussing on Diagnosis and Treatment; Palliative Care, End of Life Care, and Families and Carers; and Survivorship and Advocacy. Brief highlights for each of the panel discussions are below.

3.2.1 Cancer Prevention and Early Detection

Tom Calma – Australian Department of Health

Tom discussed the significant changes that have occurred in smoking over the last 20 years, and the decline in smoking rates. Importantly, in addition to the increasing rates of people giving up smoking, there is an increase in the amount of people who never take up smoking. Improvements are being seen in urban areas, however there is very little movement in remote Australia. Gains are being made when we empower communities to take control and we highlight positive messages. For example, highlighting the benefits of not taking up smoking, rather than just talking about the detriments of smoking. We need to do more follow up locally and regionally, and to focus on youth. Looking forward to 2030 in this area, we need to consider the impact of genomics.

Louise Lyons – Victorian Aboriginal Community Controlled Health Organisation

Louise reported the difficulties in addressing preventative health in community due to issues such as prevention being a very low priority for people, and the fact that promoting screening will result in cancer diagnoses. Screening programs are blamed for the diagnoses and have a huge impact on communities. Louise also emphasised the impact of intergenerational trauma associated with hospitals and clinics. To overcome these barriers, Louise discussed the importance of workforce training and the role of Aboriginal Liaison Officers and cultural safety of hospitals. Also, the need for patient navigators as paid positions, and not relying on volunteers in these jobs.

Lisa Whop – Menzies School of Health Research

Lisa highlighted how different the space is for cervical cancer, particularly with the advent of the HPV vaccine and testing for the virus. However, we know that Aboriginal and Torres Strait Islander people haven’t had the same benefits of the national program – so the question Lisa posed is “How do we ensure that they are included in the eradication of this cancer?” Lisa emphasised that eradicating cervical cancer is a possibility. However, to do so for Aboriginal and Torres Strait Islander people, we need the data and evidence to move forward, we need to invest in health services, and importantly we need to focus on engaging with Aboriginal and Torres Strait Islander women to affect generations of women and close this gap.

3.2.2 Culturally appropriate cancer care – with a focus on diagnosis and treatment

Siddhartha Baxi – Genesis Care

Sid talked about getting the basics right before moving on. He posed the question “What is the humanity at the heart of the situation?” The future of cancer treatment for people in regional and remote areas needs to improve and by 2030 we need to have lifted our baseline levels. Sid shared his insights from working in
remote and regional communities and providing culturally appropriate models of care. Solutions can come from technology. Sid also discussed the possibility and importance of leveraging private philanthropy and for key organisations to show social responsibility.

Bonnie King – Central Australian Aboriginal Congress Aboriginal Corporation

Bonnie opened her discussion with the important reminder that all the statistics we are reporting on are actual people and someone’s family. Bonnie discussed the barriers and the need to break these down. In her experience, it is the health workers that break down the gaps for patients. However, the social side of helping clients is also time-consuming and a lot of work. We need more of these health workers and to promote longevity in the workplace for continuity of care and support.

Sandra Miller – South Australian Health & Medical Research Institute, NICaN Ambassador

Sandra discussed the Cancer Data and Aboriginal Disparities (CanDAD) project led by Prof Alex Brown at SAHMRI. The project aims to: 1) Improve cancer diagnosis, treatment and survival among Aboriginal people; 2) Decrease the disparity between Aboriginal and non-Aboriginal peoples’ access to cancer prevention, screening and treatment; and 3) Improve the health service experiences of Aboriginal people at risk of, or diagnosed with, cancer. The findings, including the cancer journeys shared by Aboriginal cancer patients have informed the development of two important State documents; the SA Aboriginal Cancer Control Plan 2016-2021, and the SA Aboriginal Chronic Disease Consortium’s Road Map for Action 2017-2021.

Liela Murison – Townsville Hospital and Health Service

Speaking from her perspective as the Indigenous Women’s Cancer Coordinator at Townsville hospital, Liela described the ways she supports patients and families coming into the centre for cancer treatment. An important part of supporting families in this area includes telehealth, and regional centres (such as Mt Isa and Bowen) beginning to administer chemotherapy. The impact that these local services provides for patients and families is immense. Liela also reported on the financial impact that cancer and treatment has on Aboriginal and Torres Strait Islander people, especially those in communities. Often people in remote areas work on a casual basis, resulting in the need to take unpaid leave from work.

Phillip Carson – Royal Darwin Hospital

From his broad view of cancer care and patient experience gained from 40 years in the Northern Territory, Phill’s vision for 2030 is that all patients can access the best cancer care and deaths would reduce considerably. The biggest way to achieve this is through communication, mutual understanding, real partnerships, and empowering patients. Phill gave an example of the trajectory faced by lung cancer patients. This is difficult to explain to the patients, which results in: a failure to empower the patient to make decisions; resulting in misunderstandings; and the likelihood the patient won’t finish treatment. Phill highlighted the importance of Indigenous Health Educators – with interpreters if needed – to work with the patient and families. The patient is more informed and able to make knowledgeable choices. Phill also talked about the importance of cultural education, and not neglecting the power of the individual and their experience.
Sabe Sabesan – Townsville Hospital and Health Services (video)

Sabe outlined what is currently happening with telemedicine in Queensland, by providing medical consultations for Aboriginal and Torres Strait Islander patients in rural towns (see Figure 2). Using telenursing, via the Queensland Remote Chemotherapy Supervision Model, many patients in rural north Queensland towns can receive chemo and biological therapies. Sabe also discussed that by 2030 he can see an interconnected health system by connecting rural areas with large towns. All towns can receive medical consultations, chemotherapy, biological agents and clinical trials medications closer to home through telehealth. Using this integrated model, all rural towns could have access to prevention services and enhanced service capabilities. Federal and State governments need to incorporate teleoncology models into policy and planning, and resource and monitor this as a core business of health services and districts.

3.2.3 Palliative care, End of Life care, and Families and Carers

Tina Pidcock – Palliative Care, Cancer Council NSW

Tina shared her personal story and experience of caring for her mother 20 years ago as she was passing away from breast cancer. At that time Tina was not aware of palliative care services and would have utilised these services earlier if she had known. Tina now works in palliative care, providing respite for carers and palliative carers for non-Indigenous Australians. Tina discussed the burnout for staff working in this area.

Alex Huntir – Palliative Care NSW

Alex discussed the three different types of palliative care: 1) specialist palliative care is a referral-based system for people with complex needs; 2) general palliative care; and 3) public health palliative care. Alex reported that one of the big issues is helping people navigate entering the hospital system, especially those from regional areas. An important enabler to getting people the help they need is relationship and trust building between practitioners and palliative care services, and breaking down the illusion that palliative care is seen as Dr Death.

Mark Wennitong – Apunipima Cape York Health Council

Mark discussed the need to fix the fundamental trust issue that exists between government and Aboriginal and Torres Strait Islander people. He pointed out that we need to look backward to plan for the future, including incorporating traditional medicine into palliative care. Some of the things we need to consider as we’re looking forward to 2030 include: access to the best new therapies as we get more advanced (e.g., epigenetics/epigenomics); connectivity and technology as a way of informing our mob with evidence-based information; more sophisticated approaches to integrating culture into practice; integrating mental health and primary health care; being transparent about death and dying; and thinking about death earlier and what that means for families. Mark also discussed the important role health professionals can play by trying to instil confidence and hope, and promoting social and emotional wellbeing. Mark also reported the importance of the climate and environment (e.g., global warming and increasing rates of melanomas), and strategic globalisation (e.g., maximising our relationships with Asia/India) and tapping into innovative therapies.
3.2.4 Survivorship and Advocacy  
Kalinda Griffiths – University of NSW

Kalinda framed her presentation that she was speaking from the point of view as an Aboriginal woman, a cancer survivor, and an epidemiologist. Kalinda described the COSA Model of Survivorship Care, which incorporates person-centred and integrated care to give people access to equitable care and stated that there is very little work done in the area of survivorship and Aboriginal and Torres Strait Islander people with cancer. We need to be asking Aboriginal and Torres Strait Islander people, their carers, and their support people “What do you need?” Kalinda pointed to the National Aboriginal and Torres Strait Islander Cancer Framework and the Optimal Care Pathways for Aboriginal and Torres Strait Islander cancer patients as useful resources to develop models from. When developing models we need to consider the impact that this model will have on services. Kalinda then generously shared her personal story of being diagnosed with squamous cell carcinoma on her nose and needing reconstructive surgery. When she was transitioning after treatment no one told her who she was supposed to see next. There was no trail to follow. Having undergone facial surgery, this was a challenge to her identity and no one told her how this would affect her head space and emotional wellbeing. Kalinda stated that what is needed is an improvement in integrated and continuity of care.

Sanchia Aranda – Cancer Council Australia

Sanchia began her discussion by talking about growing up in New Zealand and the difference that a treaty can make for Indigenous people and the country. She reported that she could see the impact that this could have in Australia. Looking forward to 2030, Sanchia discussed the importance of Indigenous leadership in reorienting the health service model, which does not currently work for Aboriginal and Torres Strait Islander people. GPs and primary health care needs to be at the heart of the model. By 2030, Sanchia would like to see that Aboriginal and Torres Strait Islander people believe in survival and that this becomes a self-fulfilling prophecy through yarning about stories of survival. We need these stories to come alive in health services. By 2030, we will have Indigenous-designed survivorship models that hold onto the important values and invest in community development approaches.
3.3. Identifying priorities for cancer control for Aboriginal and Torres Strait Islander people

After the panel presentations delegate groups identified the top two priorities for future practice, policy, and research across the panel topic areas: Cancer Prevention and Early Detection; Culturally Appropriate Cancer Care – with a focus on Diagnosis and Treatment; Palliative Care, End of Life Care, and Families and Carers; and Survivorship and Advocacy (see Appendix 5.4 for worksheets used by attendees). A working group from Menzies synthesised the rich amount of information and identified priorities into the following eight vision statements:

◆ A **changed narrative around cancer**, with greater cancer-related health literacy and understanding by Aboriginal and Torres Strait Islander people and communities. More and better conversations about cancer, survivorship and death and dying. A better understanding by health service providers and others about what Aboriginal and Torres Strait Islander people and communities want and need.

◆ **An appropriate workforce** across the cancer control spectrum, including skilled/trained and supported Aboriginal and Torres Strait Islander staff at all levels of the system and in the full range of positions (including specialists), as well as culturally competent non-Indigenous staff who can communicate effectively.

◆ Closing the gap in cancer outcomes with a focus on **reduced prevalence of tobacco use**.

◆ Closing the gap in prevention and early detection by increasing **screening participation and increased immunisation coverage**.

◆ **Indigenous cancer care teams** established in every hospital, with appropriately skilled and supported team members (including patient navigators).

◆ Cancer care for Aboriginal and Torres Strait Islander people adheres to established **Optimal Care Pathways** (tumour specific and Indigenous OCPs) - includes family, cultural and financial support, as well as integrated care across levels of the health system and across geographical regions.

◆ **Survivors** are supported using best practice models of care, including better rehabilitation (physical and SEWB), support networks and systems, consideration of financial issues etc., so that people can re-engage with what they want to do/what’s important to them after treatment.

◆ Appropriate, culturally safe, culturally informed **end of life and palliative care** is available and accessible to support Aboriginal and Torres Strait Islander people with cancer and their families and carers.
3.4. Visions and action planning in cancer control for Aboriginal and Torres Strait Islander people

The second day of the workshop gave delegates a chance to develop action plans to achieve the vision statements outlined in Section 3.3. Groups were invited to use Futures Planning techniques, such as backcasting (see Figure 3). Backcasting enabled delegates to define a desirable future they wanted to see in 2030 and then work backwards to identify the actions that will connect that specified future to the present. These techniques were used to develop potential actionable plans required to achieve each vision, including identifying the individuals and/or organisations needed to carry the plans forward.

3.4.1. A changed narrative around cancer

**Vision:** A changed narrative around cancer, with greater cancer-related health literacy and understanding by Aboriginal and Torres Strait Islander people and communities. More and better conversations about cancer, survivorship, and death and dying. A better understanding by health service providers and others about what Aboriginal and Torres Strait Islander people and communities want and need.

**Overall goal is to use strength-based language (e.g., “cancer is survivable”).**

**Actions to achieve the vision:**

- Provide a **flexible healthcare system**.
- **Community empowerment** so that every cancer patient (and their family and community) understands their situation and there is a community awareness (including available services).
  - Sharing stories and yarning circles (as translational research)
  - Two-way learning
- **Empowering cancer survivors’ voices and stories**
  - Part of community empowerment
  - Create opportunities for dialogue between service providers, ‘systems people’ (policy, planning) and community, including through ambassadors
  - Shape policy and systems narratives
- **Capable (clinical) workforce.**
- **Understand the strength within community.**
- **Understand available services.**
- **An Aboriginal and Torres Strait Islander workforce.**
- **Suitable infrastructure** with welcoming environments, and suitable policy infrastructure and processes.
- **Changing the narrative by articulating an advocacy agenda.** Creating messages that are:
  - Clear
  - Consistent
Shaped by Aboriginal cancer survivors and people affected by cancer including family and community.

Thinking about the channels where that narrative needs to be activated (service planning, training of health professionals, policy, processes, communities) and identify existing opportunities (e.g., Aboriginal Community Controlled Health Services (ACCHOS)).

Tangible next steps:

- Bring together cancer survivors with organisations such as Cancer Councils and Menzies School of Health Research.
- Develop an advocacy framework with messages that are clear and consistent and shaped by survivors, family, communities, carers.
  - Identify individuals and organisations who need to be involved (perhaps led by ACCHOs).
  - Co-design the narrative, with community leadership (services, carers, people affected by cancer).
- Capture the experience of successful advocacy (e.g., radio shows and podcasts by VACCHO) to inform design and implementation of an advocacy agenda.

### 3.4.2. An appropriate workforce across the cancer control spectrum

**Vision:** An appropriate workforce across the cancer control spectrum, including skilled/trained and supported Aboriginal and Torres Strait Islander staff at all levels of the system and in the full range of positions (including specialists), as well as culturally competent non-Indigenous staff who can communicate effectively.

**Actions to achieve the vision:**

- *Ask consumers what they need* and conduct a gap analysis of needs (including skills and training needs that feeds into curriculum enhancement development).
- *Put policy brief forward* to every state/territory minister.
- *Form an Indigenous committee* for an advisory role—a consortium of stakeholders to ensure the issue is carried forward.
- Create job opportunities—*cancer care teams and health navigators* (e.g., 1 male and 1 female at every cancer centre) that are linked with Aboriginal medical services.
- *Resources* for patients and healthcare workers (e.g., transport, clothing, community resources folder).

### 3.4.3. Cancer Prevention – focusing on tobacco use

**Vision:** Closing the gap in cancer outcomes by focusing on reduced prevalence of tobacco use.

**Overall goal is to prevent uptake and increasing cessations through:**

- Community engagement and empowerment.
- Increase awareness (media campaigns).
- Use technology (e.g., apps) options to support quitting.
• Decrease adverse impact of smoking on environment (e.g., cigarette butts)

**Actions to achieve the vision:**

• Activities to be centred on *coordination of the current activity* in this area.
• Mapping of professions (training needs and education) to *strengthen the workforce*, including capacity and cultural awareness.
• *Increasing awareness and empowerment* by:
  o partnering with other stakeholders (e.g., heart, diabetes), ensuring that media is adequately funded for long term campaigns, providing targeted activities with priority populations (remote/very remote regions, pregnant women, young women, prisons, mental health, Indigenous peak bodies)
  o community consultation (asking smokers/families what they need/want)
• *Continuation and evaluation of existing programs*
• *Commitment from State and Territories governments* that is adequate and sustainable
• *Involvement of key stakeholders*, including: Peak bodies, State and Territory governments, Professional colleges, Communities, Community controlled organisations, Justice system, Mental health sector, Housing, Education, Employment.

### 3.4.4. Cancer Prevention and Early Detection – screening and immunisation

**Vision:** Closing the gap in prevention and early detection by increasing screening participation and immunisation coverage.

**Actions to achieve the vision across major cancer types:**

**Liver cancer**

• *Reducing liver cancer deaths* through immunisation and treatment
• *Understanding epidemiology* of liver cancer in Indigenous people
• Identify current evidence on *Hepatitis B vaccination rates* and reducing the gap in vaccination coverage
• Conduct an environmental scan and identify *who is working in this space*

**Bowel cancer**

• *Understanding new test developments* and identifying ideal program requirements of test
  o Receive appropriate follow-up on a positive screen
  o Monitoring new test developments (e.g., develop a less heat/time sensitive test)
  o Outcomes to SAHMRI project – assess additional research required
• Research to understand why Indigenous participants are less likely to have a colonoscopy
• Indigenous participation to be at least equal to overall participation (at least 60%) in the National Bowel Cancer Screening Program (NBCSP)
  o Age of test to be optimised for Indigenous people
  o Increased bowel screening awareness and understanding amongst Indigenous population
  o PHCs discuss and recommend bowel screening (and potentially offer kit)
  o Implementation of current study – Alternative Pathways to Bowel Screening for Indigenous People (CIA Garvey) to be finalised and evaluated
- NBCSP campaigns appropriate for Indigenous audience and/or completed by specific Indigenous communication activities
- Local level grants for community led bowel screening awareness activities
- Involve Menzies, Department of Health, SAHMRI, Cancer Councils and other NGOs, community, ACCHOs, PHNs

**Breast cancer**
- Achieve parity *in screening* participation
- Consolidate existing research (including grey literature)
- Conduct similar activities to those listed below in Cervical cancer (e.g., community awareness, evaluation of activities etc.)

**Cervical cancer**
- Close screening gap
- Reduce incidence, mortality, and improve survival
- Achieve World Health Organisation elimination goal for all Australian women
- By 2030 self-collection a main pathway for all women
- Real-time reporting of Indigenous women’s participation and outcomes
  - Develop a reporting loop of Indigenous status from patient through to provider, pathology labs, register, and back out
  - Operational register
  - High priority for Government and Department of Health (need a political champion, coalition of female MPs, nonpartisan)
- Create a safe pathway through screening, diagnosis, and treatment for Indigenous women
- Activities to achieve these aims include:
  - Community awareness advocates
  - Effective outreach through community days
  - Indigenous staff in screening programs – those who screen themselves become champions
  - Evaluation of awareness and community activities
- Involve Menzies, Department of Health, PHC/GPs, champions such as Fiona Stanley and Linda Burney

**HPV Vaccination**
- Get over sustained *80% vaccination coverage* – this is based on modelling in a meta-analysis (don’t need 100% to stop local circulation) by Brisson et al. 2016.
  - We need to be able to measure Indigenous coverage accurately at national, state and local level
  - Understand the process of HPV vaccination for Indigenous students – acceptability and barriers
- Assess outcomes of work currently undertaken (Whop et al.)
### 3.4.5. Indigenous cancer care teams

**Vision:** Indigenous cancer care teams being established in every hospital, with appropriately skilled and supported team members (including patient navigators).

**Actions to achieve the vision:**

- *Integrated cancer health services* that are holistic and meets the needs of the Indigenous community
- *Permanent positions for cancer care coordinators* (not temporary)
- *Indigenous cancer health navigators* (male and female) at each cancer centre, linked with the local Aboriginal Medical Service as support for additional services
  - Navigator to coordinate after care follow-up and counselling if needed
- *Resources* for patients and staff (with printed materials being culturally appropriate), including community resources and a register of online resources
- Research is needed to identify the *best model of care* and then ensure the *translation* of this into practice
- We need to involve the community, Aboriginal workforce, advocacy groups, funding bodies (e.g., Area Health Services), certification bodies (state and national), other key stakeholders

**Tangible next steps:**

- Appoint an Indigenous leader to co-ordinate a *policy brief* on the need for Cancer Care Coordinators; highlighting the benefits, costs and the cost benefit to the health system
- Put this *proposal* to every state Aboriginal Director and state Health Minister
- Conduct a *forum with all key stakeholders* to draft an Action Plan
  - Conduct *community consultations* regarding the Action Plan
  - Involve *key community stakeholders* in an Advisory Role to ensure implementation and effectiveness of the plan
    - Involve community organisations to *support local initiatives* (e.g., providing care for patient transport)
  - Establish *Indigenous support groups for cancer survivors*
  - The stakeholder group to meet regularly to *adapt the plan to meet emerging needs and issues*

### 3.4.6. Cancer Care adhering to Optimal Care Pathways (OCP)

**Vision:** Cancer care for Aboriginal and Torres Strait Islander people adhering to established Optimal Care Pathways (tumour specific and Indigenous OCPs) – includes family, cultural and financial support, as well as integrated care across levels of the health system and across geographical regions.

**Actions to achieve the vision:**

- *Identify what data is needed*
  - For example, include a checklist in the OCP
  - We need to be able to evaluate and monitor OCP use and outcomes
  - Identify which aspects of the OCPs are incentivised and able to be measured
- *Workforce capacity and capability*
  - Funding of positions in PHCC/prevention/screening
Chronic Disease teams already exist (SNAP Frameworks with a focus on diabetes and cardiology, not on cancer). Identify whether we can embed cancer care into this existing framework that is already working.

- Training GPs, health workers in the OCPs
- Improving health literacy for patients and carers
- Ensure integration and communication across levels of the health system including hospitals, cancer care and outreach, treatment centres, Aboriginal Medical Services, PHCC.

In the tertiary setting we need:

- Cancer care coordinators in the tertiary setting who can:
  - Adapt to emerging issues
  - Improve health literacy and communication
  - Help with linking to services and resources, and be a link between PHCC and tertiary care
- Sustainable funding for these coordinators, Indigenous leadership and support to work out the details, and cultural safety for staff and patients
- Accurate data (e.g., Qld trial site for including cancer stage and treatment in Cancer Registry data)
- To be able to identify and understand delays in receiving cancer care (e.g., transport)

### 3.4.7. Survivorship

**Vision:** Survivors being supported using best practice models of care, including better rehabilitation (physical and SEWB), support networks and systems, consideration of financial issues etc., so that people can re-engage with what they want to do/what’s important to them after treatment.

**Actions to achieve the vision:**

- **Develop Best Practice Models of Care (Gold Standard) for Indigenous Cancer Survivorship**
  - Obtain funding to hold a roundtable led by cancer survivors, with nungkaris (healers), community stakeholders, family networks, carers, clinicians and other health professionals, primary healthcare practitioners, community elders, researchers and evaluators. Write-up the models of care.
  - The conversations have already started but we need to hold a Roundtable to create the evidence around Indigenous cancer survivors’ needs and experiences and formalise a model of care.
  - Conduct a panel in the Lowitja Conference on Cancer Survivorship
  - Create evidence around Indigenous cancer survivors’ needs and experiences

- **Cultural safety in clinical practice**
  - Obtain recognition from clinicians
  - Provide opportunities for patients to be given option to combine Western and traditional medicines
  - Advocacy and education for clinicians to incorporate traditional treatment options into their consideration.

- **Support carers in taking care of their family members with cancer**
First steps involve research to identify and explore carers’ supportive needs and experiences, and the best ways to provide support.

Long term aims are to provide education for the community and family members about survivorship (including possible outcomes of diagnosis and side-effects), provide support (including counselling) to the carers from the moment of diagnosis, reduce ‘survivors and carers guilt’, reduce risk of family conflict due to the diagnosis of cancer.

- Support the patients and the carers in their own communities and in their own environment
  - Lobbying the government for funding to develop and trial a model for a culturally appropriate and safe local Point of Contact
  - Establish a culturally appropriate and safe local Point of Contact who knows about cancer and the system as well so that the patients can be referred (directive role as well as to provide required support)
  - Yearly stipend to cancer survivors for them to go and provide education and support to newly diagnosed patients

3.4.8. Palliative and End of Life Care

**Vision:** Appropriate, culturally safe, culturally informed end of life and palliative care is available and accessible to support Aboriginal and Torres Strait Islander people with cancer and their families and carers.

**Actions to achieve the vision:**

- For all Indigenous and non-Indigenous healthcare staff across Australia to complete training in the Program of Experience in the Palliative Approach (PEPA). Long-term funding is required to support PEPA. Research is needed to evaluate whether PEPA can be delivered quicker, cheaper and scalable.
- We need to develop guidelines on end of life care for Indigenous Australians. All palliative care services to adhere to an expected level of provision (support from specialists as needed).
- Demonstrate value from the Palliative Care Outcomes Collaboration (PCOC), through which patient outcome data for palliative care patients is routinely collected, analysed and fed back to palliative care providers Australia-wide to drive improvements in patient outcomes. We need to improve Indigenous identification and assess what research can be conducted using the PCOC data.
- Ensure that a high percentage of patients get early palliative care intervention. This topic has momentum already, hence partnering with programs/organisations such as PEPA can be valuable. Research is needed to identify pinch points during the palliative care journey.
4. Summary and conclusions

The Shaping the Future: Indigenous People and Cancer 2018 Roundtable gave us an opportunity to consider current issues and trends and envisage a future that best supports Aboriginal and Torres Strait Islander people affected by cancer. To do this we involved Aboriginal and Torres Strait Islander people affected by cancer and the key people working in research, policy and practice to the 2018 Roundtable.

A key outcome was the identification of eight key vision statements in cancer control for Aboriginal and Torres Strait Islander people, and workshopping possible plans and actionable goals focussed in these areas. In summary these plans involved:

- **Changing the narrative around cancer** and using strength-based language, creating a flexible health care delivery model that engages with Aboriginal and Torres Strait Islander people across their lifespan, and empowering communities and individuals.

- **Supporting an appropriate workforce** across the cancer control spectrum by asking consumers what they need, advocating to every state/territory minister, creating job opportunities that cut across different sectors (Aboriginal Medical Services through to tertiary care), and providing appropriate resources for patients and healthcare workers.

- **Closing the gap in cancer outcomes with a focus on reduced prevalence of tobacco use** through preventing uptake and increasing cessations. This can be achieved by strengthening the workforce, partnering with other stakeholders to create long-term awareness campaigns, continue existing successful programs and evaluate the outcomes, and ensure sustained commitment from state/territory government.

- **Closing the gap in prevention and early detection by increasing screening participation and immunisation coverage** – targeted approaches for different cancer types that are based on gaining an understanding of the consumer perspective on barriers and enablers, and developing strategies to increase participation that involve multi-layered key stakeholders (government, community-controlled organisations, champions, NGOs etc.)

- Establish **Indigenous cancer care teams** to provide sustained and integrated cancer health services, which can be achieved via navigators, appropriate resources, and identifying and implementing best models of care.

- Providing cancer care for Aboriginal and Torres Strait Islander people that adheres to the established **Optimal Care Pathways** (tumour specific and Indigenous OCPs) can be achieved by initially identifying how to assess adherence, ensuring there is integration and communication across the levels of health care system and across geographical regions, creating sustainable funding for cancer care coordinators, and promoting family, cultural and financial support.

- Develop **best practice models of care for Indigenous Cancer Survivorship** (including better rehabilitation, support networks and systems, consideration of financial issues etc.), so that people can re-engage with what they want to do/what’s important to them after treatment.

- Provide **appropriate, culturally safe, culturally informed end of life and palliative care** that is available and accessible to support Aboriginal and Torres Strait Islander people with cancer and their families and carers.

We invite you to take the findings outlined in this report and consider the ways in which you, and your collaborators, can implement the vision statements into actions to improve cancer outcomes for Aboriginal and Torres Strait Islander people.

5. Appendices

Appendix 5.1: Discover-TT and STREP CaCindA overview
Appendix 5.2: List of Roundtable Attendees
Appendix 5.3: Roundtable Agenda
Appendix 5.4: Day 1 & 2 Worksheets
Appendix 5.1: Discover-TT and STREP CaClndA overview

DISCOVER-TT and STREP CaClndA: what we have achieved

The Centre for Research Excellence (NIMHRC funded), in Discovering Indigenous Strategies to Improve Cancer Outcomes Via Engagement, Research Translation and Training (DISCOVER-TT) was established in 2015 with an initial funding of $4 million. In 2017, DISCOVER-TT joined with the Cancer Council NSW (STREP CaClndA). At both stages, 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 2015.

Capacity Building

The National Indigenous Cancer Network (NICAN) was established to identify priorities for Indigenous people with cancer, including their needs, families and communities. Health brings together Indigenous audiences, cancer survivors, service providers, researchers and health professionals from a broad range disciplines, including private sector, government, and NGO organisations. Through NICAN, we can connect communities, which are cancer survivors and caretakers, sharing stories and helping others understand cancer and the importance of screening. www.nican.info

Bowel Screening

The National Indigenous Bowel Screening Pilot hopes to make bowel screening more accessible for Indigenous Australians and improve screening rates. Consistent with 2016-17, many of the barriers to participation could be addressed if eligible Indigenous people received the screening kit directly from their usual health professional at their local health care service. To address these barriers, the Pilot involves around 30 primary health care centres handling 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 in patients and clinically reliable and valid. Increased the confidence of staff. The tool is currently being implemented into routine care in several hospitals. We are now developing a tool to assess the unmet needs of caregivers of Indigenous cancer patients.

Cervical Screening

Whisper: all found Indigenous women participated in cervical screening compared to non-Indigenous women (65.1% vs 87.9%) as shown below. Recent findings showed that for the third of Indigenous women that participated 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 services study to better understand the views of women who both do and don’t screen.

Cancer Framework

In 2015, the National Aboriginal and Torres Strait Islander Cancer Framework was developed to address the needs of Aboriginal and Torres Strait Islander people.

THE FUTURE: TACTICS 2019-2023

New NIMHRC funded: ‘TACTICS’ OCR - Targeted Approaches To Improve Cancer Services for Aboriginal and Torres Strait Islander Australians.

This new program of work aims to:

1. Increase cancer prevention and early detection through immunisation and screening.
2. Improve diagnosis and treatment though health service innovation.
3. Provide a greater degree of care to enhance psychosocial well-being of Indigenous cancer survivors, their families and carers across the cancer continuum.

TACTICS is an Indigenous-led research program with collaborations between James Cook University, school of health research, School of Medicine, University of Queensland; University of Sydney; University of Western Sydney; James Cook University; and Australian Indigenous Health Service. This CRC will enable partners to analyse and report the care of research in Indigenous communities, cancer policy and practice, and also continue to build research capacity through training the next generation of researchers in Indigenous cancer control.
## Appendix 5.2: List of Roundtable Attendees

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<td>Baker</td>
<td>Mick (Dhinawan)</td>
<td>Roundtable facilitator</td>
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<td>Pidcock</td>
<td>Tina</td>
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<td>Willmett</td>
<td>Neil</td>
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# Appendix 5.3: Roundtable Agenda

## TUESDAY 11 SEPTEMBER | 8.30am – 4pm

- Registration, tea and coffee available.

  - Welcome to country and smoking ceremony performed by Gadigal Elder Uncle Charles (Chicka) Madden and Gumaroy. MC welcome and housekeeping by Dhinawan.
  - Our shared history, where we were, where we are, and why we are here
    - Presented by Gail Garvey, Menzies School of Health Research
  - Mapping the landscape. Where we are today to the mid-range future and more distant future. What is the world going to look like – imagining a future in 2030? It’s only as far away as 2006.
    - Presented by Jenny Brands, Menzies School of Health Research

  **Morning tea**

  - **Panel Discussion A** – Cancer prevention and early detection
    - Tom Calma – Australian Department of Health
    - Louise Lyons – Victorian Aboriginal Community Controlled Health Organisation
    - Lisa Whop – Menzies School of Health Research
  - **Panel Discussion B** – Culturally appropriate cancer care – focusing on diagnosis and treatment
    - Siddhartha Baxi – Genesis Care
    - Phillip Carson – Royal Darwin Hospital
    - Bonnie King – Central Australian Aboriginal Congress Aboriginal Corporation
    - Sandra Miller – South Australian Health & Medical Research Institute, NICAmbassador
    - Liela Murison – Townsville Hospital and Health Service

  **Lunch**

  - Come back from lunch and join a group discussion around the Panel Presentations A & B. During discussion groups, identify top two priorities from the panel topics that can be explored further.

  - **Panel Discussion C** – Palliative care, End of Life care, and Families and Carers
    - Tina Pidcock – Palliative Care, Cancer Council NSW Hunter
    - Alex Hunt – Palliative Care NSW
    - Mark Wenitong – Apunipima Cape York Health Council
  - **Panel Discussion D** – Survivorship and Advocacy
    - Sanchia Aranda – Cancer Council Australia
    - Kalinda Griffiths – University of NSW

  **Afternoon tea**

  - Come back from afternoon tea and join a group discussion around Panels C & D. During discussion, groups identify top two priorities to be explored further.

  **Wrap up, conclusion of first day.**

## WEDNESDAY 12 SEPTEMBER | 8.30am – 3pm

- Tea and coffee available

  - Summary of Panels A, B, C and D, and group discussions.
    - By Joan Cunningham, Menzies School of Health Research
  - Workshop: using the identified priorities from day one, what needs to happen to get to where we want?
    - Lead by Jenny Brands, Menzies School of Health Research

  **Morning tea**

  - Continue workshopping the actions needed to get to priorities. Identify individuals/organisations that need to be involved to achieve each action. Explore consequences of actions.

  **Lunch**

  - Each group to share their discussion and plot the stepping stones for future action.

  **Wrap up of two days.**
# Appendix 5.4: Day 1 & 2 Worksheets

**Futures Planning worksheet – 11th September 2018**

**Topic area:**

- [ ] Cancer Prevention & early detection
- [ ] Cancer Care – diagnosis & treatment
- [ ] Palliative Care and End of Life Care
- [ ] Families & Carers
- [ ] Survivorship
- [ ] Advocacy
- [ ] Other

**Identify the top 2 priorities in your area of discussion:**

(Briefly describe the priority and why this is important to work towards in this area)

1. 

2. 
## Backcasting

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<th>2030</th>
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Consider possible changes in:
- Economy
- Environment
- Technology, scientific developments
- Population
- Social structure
- Government, law

Consider factors like:
- Who needs to be involved?
- Access to quality and appropriate health care
- Health knowledge, attitudes
- Communication, information use
- Workforce (roles, training)
- Barriers and enablers to change

### Goal (where do we want to get to)

<table>
<thead>
<tr>
<th>Goal</th>
<th>High level aims</th>
<th>Activities to achieve these aims (including but not limited to research required)</th>
<th>Who needs to be involved? (may differ across activities)</th>
<th>Which steps can be taken now?</th>
</tr>
</thead>
</table>
We thank all the delegates who keenly participated in the Roundtable.