



Aboriginal and Torres Strait Islander 'State of Knowledge' on Cancer Roundtable: Report

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Note on Terminology: In this report the term 'Aboriginal people' is used to identify the First Peoples of Australia and refers specifically to Aboriginal people residing in Victoria. The term 'Aboriginal and Torres Strait Islander peoples' is used to refer to and recognise the two unique Indigenous populations in Australia. The term 'Indigenous' refers collectively to the First Peoples of Australia, New Zealand, North America, and other countries around the globe. 'Non-Indigenous' is used to refer to those who do not identify as a member of the community of First Peoples of their respective countries.

Table of Contents

| About the Rethinking Cancer, Raising Hope Roundtable | IV |
|---|----------------|
| Co-hosts and Roundtable designers, evaluators and report collaborators (1) Onemda VicHealth Group | I∖ /V |
| (2) Peter MacCallum Cancer Centre | IV |
| Abbreviations | IV |
| Executive Summary | 1 |
| Key Priority Areas for Future Action | 3 |
| Background to the Roundtable | 4 |
| Cancer statistics | 4 |
| Framework for addressing cancer | 5 |
| Roundtable Opening Addresses: Highlights | 6 |
| Welcome: Aunty Diane Kerr | 6 |
| Welcome: Ms Dale Fisher | 7 |
| Opening Address: Dr Pradeep Phillip | |
| Closing the Gap Properly | 3 |
| Day 1: Presentations and Discussions | 10 |
| Introduction: Professor Kerry Arabena | 10 |
| Presentation: Ms Jill Gallagher AO | 10 |
| Panel Discussion: Collaboration makes a difference | 11 |
| Themes to be explored in the development of a Cancer Action Plan for Victoria | 12 |
| Key enablers | 12 |
| What is already known on this subject | 12 |
| Key messages: Screening, diagnosis and treatment | 12 |
| Individual and family case management | 13 |
| Community-based approaches | 13 |
| Relationship and network development Benefits of collaboration | 14 14 |
| Deficition of Collaboration | 1- |
| Day 2: Presentations and Discussions | 16 |
| Workshop 1: Reducing the risk of cancer | 16 |
| Gap analysis: Workshop 1 | 16 |
| Workshop 2: Find cancer early | 17 |
| Gap analysis: Workshop 2 | 17 |
| Workshop 3: Management and support during and after treatment | 17 |
| Gap analysis: Workshop 3 | 18 |
| Workshop 4: Care and support at end of life Gap analysis: Workshop 4 | 19 19 |
| Cap analysis. Workshop T | 13 |
| Appendix 1: Attendees at the Roundtable | 20 |
| Appendix 2: Rethinking Cancer, Raising Hope Roundtable Program | 21 |
| | - - |

About the Rethinking Cancer, Raising Hope Roundtable

Co-hosts and Roundtable designers, evaluators and report collaborators

Professor Kerry Arabena (1), Dr Zoe Wainer (2), Ms Alison Hocking (2), Ms Leanne Adams (2) and Ms Viki Briggs (1)

(1) Onemda VicHealth Group

Onemda VicHealth Group (Onemda), located in the Indigenous Health Equity Unit at the Melbourne School of Population and Global Health, is committed to research and teaching that is underpinned by Aboriginal community development and will lead to long-term improvements in Aboriginal health. Onemda has built an academic program based on Aboriginal and Torres Strait Islander values and principles, but which also respects the contribution and cultural background of all those who work with us. Our approach brings perspectives from staff in a variety of academic disciplines including health sciences, social sciences, history, political science, education, health promotion, public health and child health. We collaborate with many departments in the University of Melbourne, where we are based, and advocate for community-driven research both within and outside the university.

(2) Peter MacCallum Cancer Centre

The Peter MacCallum Cancer Centre (Peter Mac) has a deep commitment to Closing the Gap in access to care and outcomes for Aboriginal and Torres Strait Islander patients. Peter Mac has a strategic framework to guide its response to the unique challenges that Aboriginal and Torres Strait Islander patients face in preventing and treating cancer. It has also undertaken some promising initiatives in researching Aboriginal and Torres Strait Islander health and cancer including clinical pathways and supportive care needs. Peter Mac has centred its Aboriginal and Torres Strait Islander health strategy on: clinical care, research, employment and community engagement.

Abbreviations

ACCHOs Aboriginal Community Controlled Health Organisations

ALOs Aboriginal Liaison Officers

CCV Cancer Council Victoria

CEO Chief Executive Officer

NACCHO National Aboriginal Community Controlled Health Organisation

Onemda VicHealth Group

Peter Mac Peter MacCallum Cancer Centre

SVHM St Vincent's Hospital Melbourne

VACCHO Victorian Aboriginal Community Controlled Health Organisation

VAHS Victorian Aboriginal Health Service

VAPCP Victorian Aboriginal Palliative Care Project



The aim of the Roundtable was to improve collaboration in clinical care and research into cancer in Aboriginal and Torres Strait Islander populations, which in turn will improve cancer prevention, control and treatment for Aboriginal communities in Victoria.

On 25–26 August 2014, the Onemda VicHealth Group and the Peter MacCallum Cancer Centre co-hosted the Rethinking Cancer, Raising Hope: Aboriginal and Torres Strait Islander 'State of Knowledge' on Cancer Roundtable at the Melbourne Museum's Treetops Room. The aim of the Roundtable was to improve collaboration in clinical care and research into cancer in Aboriginal and Torres Strait Islander populations, which in turn will improve cancer prevention, control and treatment for Aboriginal communities in Victoria.

Bringing together 45 participants from cancer services, and community controlled, mainstream, government and non-government agencies, the Roundtable's focus was on the provision of cancer prevention and support services for Aboriginal and Torres Strait Islander communities across Victoria. Participants heard from service providers, agency managers, peak bodies and representative organisations, as well as, importantly, from individuals and carers, some of whom shared personal stories about their cancer journey. The aim of the Roundtable was to:

- Document current best practice strategies to Close the Gap in cancer mortality rates for Aboriginal and Torres Strait Islander peoples living in Victoria
- Share experiences and learnings from past and current cancer-focused strategies
- Identify considerations required to overcome challenges when implementing cancer education, health promotion and other services, particularly for those under-screened populations
- Learn how to shift community's perception from 'cancer is a death sentence' to 'cancer is preventable and curable, and can be treated and managed if caught quickly enough'
- Identify the best approach to monitoring and evaluating cancer-focused initiatives'

 Gain maximum support for a coordinated approach to the development of a Cancer Action Plan for Aboriginal and Torres Strait Islander peoples living in Victoria.

In the absence of either a national or State Cancer Action Plan specifically focusing attention on the health and wellbeing of Australia's First People, participants put forward suggestions for ways to strengthen cancer prevention strategies and to promote quality-of-life measures for Aboriginal people with cancer and their families. These include the need for:

- Services and agencies in Victoria to engage with and strengthen Aboriginal communities in all approaches to cancer prevention and delivery of care, and to promote improved quality of life for individuals and carers
- Agencies to better support patients and their families by developing seamless services, cultural sensitivity and collaboration
- Research-informed services to be delivered through a focus on data linkage, patient journeys, and improving the capacity of existing services to improve their reach and engagement with Aboriginal and Torres Strait Islander patients and their families
- Opportunities for the professional development of staff working with Aboriginal and Torres Strait Islander patients and the implementation of strategies by communities to encourage health-seeking behaviour of people at risk of cancer – e.g. under-screened populations
- Cancer-specific peak bodies collaborating on the development of State-wide Action Plans to guide implementation in regional jurisdictions, with plans needing to be consistent with, and be seen to localise, any national frameworks.

Over the two days, participants engaged in cultural awareness-raising activities through the Bunjalaka Exhibition, shared learnings from successful cancer initiatives, and joined together in political advocacy for the development of a Cancer Action Plan for Victorian Aboriginal people. They also engaged in key discussions around:

- health promotion efforts targeting the community and health care providers
- the role of advocacy and joined-up action
- the use of monitoring and evaluation

- examples of innovation in much-needed initiatives around the State
- replicating lessons learned from previous experiences and local interventions.

This Report on the outcomes of the Roundtable is the first step in defining what should be included in a Cancer Action Plan for Victoria, with an emphasis on improving access by at-risk Aboriginal and Torres Strait Islander Victorians. It also aims to add to the development of a national approach to cancer care for Australia's First Peoples.



Professor Kerry Arabena and Ms Dale Fisher, co-organisers of the Rethinking Cancer, Raising Hope Roundtable

Key Priority Areas for Future Action

Roundtable participants identified the following areas for follow-up:

- Develop a coordinated Cancer Action Plan for Victoria – in which there is a focus on Aboriginal community engagement, coordination of services and a commitment to evidence-informed strategic initiatives.
- Understand and address barriers to early detection – find out how, why and where Aboriginal people go or don't go for cancer treatment
- Demonstrate how the work of a Cancer Action Plan, with support from strategic alliances, can help to Close the Gap in cancer outcomes for Aboriginal people in Victoria.
- Support a strong, focused workforce that engages communities on early screening and detection initiatives. This will require a commitment to Health Care Provider training and support for the uptake of innovative approaches to cancer education, detection, treatment and after-care, and home-based support.

- Develop Aboriginal capacity building in cancer research and cancer control, particularly in oncology.
- Pilot innovative transition services for patients with cancer between institutions and home.
- Develop a greater understanding of the needs of other people involved in a patient's cancer journey.
- Improve the patient pathway so Aboriginal people can access timely, appropriate care and are supported as needed.
- Promote data linkage and data strengthening opportunities.
- Find local explanations for epidemiological data disparities.

Participants also asked for the development process to include opportunities to meet again to discuss appropriate and acceptable strategies for Aboriginal and Torres Strait Islander cancer care, and that further research and community consultation take place.

In a Victorian first, Indigenous leaders and healthcare advocates from around the state teamed with cancer experts from across the spectrum of disease to understand why mortality rates from cancer for Aboriginal and Torres Strait Islander Ipeoplel are an estimated 1.5 times greater than for non-Indigenous Australians, despite similar rates of incidence... ¹

-NACCHO

NACCHO 2014, 'Indigenous leaders and cancer experts join forces to close the gap in cancer outcomes', *NACCHO News*, 10 September. Available at: www.nacchonews.com/blog/indigenous-leaders-and-cancer-experts-join-forces-to-close-the-gap-in-cancer-outcomes.

Background to the Roundtable

Leaders in health and cancer services for both Aboriginal and non-Indigenous government and non-government health organisations were invited to attend the Roundtable to consider the statistics of cancer for Aboriginal people, to share information about current health initiatives, and to participate in setting some key directions for the development of Cancer Action Plans, particularly for Victoria.

Cancer statistics

The current statistics relating to cancer for Aboriginal and Torres Strait Islander populations nation-wide are sobering, and are summarised as follows.

Cancer incidence and mortality rates are higher for Aboriginal Australians

In 2004–08, Aboriginal Australians had a higher rate of new cancer cases diagnosed than other Australians (461 compared with 434 per 100,000) using age-standardised data, with lung cancer the most commonly diagnosed among Aboriginal Australians. In 2007–11, the age standardised cancer mortality rate was higher for Aboriginal Australians than for other Australians (252 compared with 172 per 100,000), with lung cancer the leading cause of cancer death for Aboriginal Australians.

Cancer survival is lower for Aboriginal Australians

Aboriginal Australians diagnosed with cancer between 1999 and 2007 had a 40 per cent chance of surviving for at least five years, which was lower than for other Australians (52%).

Fewer cancer-related hospitalisations occurred for Aboriginal Australians

From 2006–07 to 2010–11, Aboriginal Australians were less likely to be hospitalised for a principal diagnosis of cancer compared with other Australians (113 compared with 170 per 10,000), although they had longer hospitalisations than other Australians (9.6 compared with 7.7 days on average).

Higher prevalence of cancer-related modifiable risk factors

Aboriginal and Torres Strait Islander peoples have higher rates of certain lifestyle risk factors, which can partly explain some cancer incidence and mortality patterns such as:

Liver cancer: Aboriginal Australians are three times as likely to develop, and 3.3 times as likely to die from liver cancer and had a lower chance of surviving another (1) year (21% compared with 33%) than other Australians. Higher rates of risky alcohol consumption and a greater prevalence of hepatitis B infection in this population group may be contributing factors.

Cervical cancer: Aboriginal females are 2.8 times as likely to develop and 3.9 times as likely to die from cervical cancer and had a lower chance of surviving another five years (51% compared with 67%) than other Australian women. A contributing factor in the higher rates in Aboriginal females could be lower rates of cervical screening for this population group.

Breast cancer in females: Aboriginal women diagnosed with breast cancer in 2003–07 had a 100 per cent higher risk of dying from any cause by 2010 than non-Indigenous females. The poorer prognosis could be at least partly explained by the lower participation of Aboriginal women in breast cancer screening (36%) compared with non-Indigenous females (54%). Reports from several Australian States and Territories indicate that cancer mortality rates are higher for Aboriginal and Torres Strait Islander peoples than other Australians for all cancers combined and for several cancer sites.²

² Australian Government, Australian Institute of Health and Welfare (AIHW) & Cancer Australia 2013, Cancer in Aboriginal and Torres Strait Islander Australians: An Overview, Cat. No. CAN 75, AIHW, Canberra. Available at: http://www.healthinfonet.ecu.edu.au/uploads/resources/26088_26088.pdf.



Lung cancer: Aboriginal Australians are 1.9 times as likely to develop and die from lung cancer as other Australians. A contributing factor may be the higher prevalence of smoking among Aboriginal Australians (38% compared with 18%).

In 2013 there were more than 100 new diagnoses of cancer and more than 40 cancer-related deaths in Victorian Aboriginal and Torres Strait Islander peoples. Overall, the cancer incidences were higher than for non-Indigenous women, but male rates did not differ significantly. However, importantly mortality rates were significantly higher for Aboriginal and Torres Strait Islander peoples than for both non-Indigenous male and female Victorians.³

Framework for addressing cancer

To date, there have been some major health initiatives around cancer in Victoria, but few have sought to bring together Aboriginal services, cancer agencies, carer groups, health promotion advocates and patients with hospital-based services to address issues related to cancer prevention, treatment, care and cure. Victoria's blueprint for Aboriginal health, Koolin Balit: Victorian Government Strategic Directions for Aboriginal Health 2012–2022,4 for example, contains interlocking recommendations that collectively seek to identify and address the systemic challenges to the access and use of cancer services by Aboriginal and Torres Strait Islander Australians, and provides the framework through which current challenges faced by patients, their families and service providers are met. The Koolin Balit strategy broadly aims to:

- close the gap in life expectancy for Aboriginal people living in Victoria
- reduce the differences in infant mortality rates, morbidity and low birth weights between the general population and Aboriginal people

• improve access to services and outcomes for Aboriginal people.

Efforts are framed by six key priorities:

- 1. A healthy start to life
- 2. A healthy childhood
- 3. A healthy transition to adulthood
- 4. Caring for older people
- 5. Addressing risk factors
- 6. Managing illness better with effective health services.

Three enablers provide a foundation for, and support their achievement of, these key priorities:

- 1. Improving data and evidence
- 2. Strong aboriginal organisations
- 3. Cultural responsiveness.

Koolin Balit builds on the Victorian Health Priorities
Framework 2012–2022,⁵ with both focusing on increasing awareness among people at risk of developing cancer, people with cancer and their carers so as to capture most of those needing checks and services. There also needs to be consideration given to the identification of actions and partnerships that will address challenges when implementing cancer education, health promotion and other services, particularly for those under-screened populations.

In Victoria, part of the challenge includes the identification of best approaches to monitoring and evaluating cancer-focused initiatives. That is why the *Koolin Balit* framework needs to inform, and be accommodated, in any initiative that coordinates approaches to the development of a Cancer Action Plan for Aboriginal and Torres Strait Islander peoples living in Victoria.

³ V. Thursfield et al. 2014, Cancer in Victoria: Statistics and Trends 2013, Cancer Council Victoria, Melbourne.

⁴ Department of Health Victoria 2012, Koolin Balit: Victorian Government Strategic Directions for Aboriginal Health 2012–2022, Victorian Government, Melbourne.

⁵ Department of Health Victoria 2011, Victorian Health Priorities Framework 2012–2022: Metropolitan Health Plan, Victorian Government, Melbourne.

Roundtable Opening Addresses: Highlights

In bringing together people from different organisations, institutions and parts of the country, we wanted to impress upon those working in this area the importance of gatherings such as this one, and to establish a firm base for lobbying actions and initiatives. We wanted to commit to community-based approaches, to the facilitation of strengthening activities, of joined-up action and a 'show of force' from our health leadership in Victoria to achieving positive outcomes in this field.

We were privileged to acknowledge the land of the Wurundjeri peoples from the Kulin Nation, and pay our respects to their Elders both past and present, as well as those other Aboriginal and Torres Strait Islander people in the room with us. We also acknowledged those working tirelessly in the cancer sector for their contribution to our society as a whole, and for pursuing the goal of equity for all.

Welcome: Aunty Diane Kerr

Elder, Wurundjeri Peoples, Kulin Nation

My family have experienced cancer. I have personal experience with cancer. What you are doing is vitally important for all of us. We have to find a way to live and work in harmony.

- Aunty Diane Kerr



Wurundjeri Elder Aunty Diane Kerr welcomes participants to the Rethinking Cancer, Raising Hope Roundtable

Welcome: Ms Dale Fisher

CEO, Peter MacCallum Cancer Centre

We know that Aboriginal people are twice as likely than non-Indigenous Australians to be admitted to hospital with a potentially preventable condition and are less likely to receive the recommended treatments than non-Aboriginal people with the same condition.

We know that mortality rates from cancer for Aboriginal and Torres Strait Islander Australians are, alarmingly, an estimated 1.5 times greater than for non-Indigenous Australians – despite similar rates of incidence.

And we know that Indigenous people are significantly more likely to have cancers that are diagnosed at a later stage and with a poor prognosis.

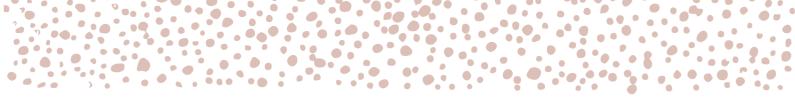
Speaking as the Chief Executive of Australia's only public hospital solely dedicated to cancer I say this is, quite simply, unacceptable. And I know that you and your colleagues clearly agree.

In what has been an extraordinary response, we've been inundated with requests from experts and community members from across the nation wanting to participate in this Roundtable. We all agree that we have an urgent problem but, importantly, it's one that many people – people with the knowledge and the know-how – are very keen to solve.

Of course, we're not going to find, in these two days, solutions to replace decades of prescriptive models, but in starting the conversation we will begin to understand the factors that influence poor care outcomes.

This open dialogue between Indigenous communities, health care workers, government and advocates is crucial to building our Indigenous cancer prevention and cancer management capacity.

In these two days, you will put the spotlight on the entire cancer spectrum – from prevention to palliative care and survivorship – and look for solutions ranging from clinical pathways and tailored approaches to



care, and to ensuring that our hospitals and clinics are environments in which Indigenous patients feel included, respected and safe.

With these conversations we can, collectively, start to design strategies, remove barriers and commence the journey to shaping our effort appropriately so that one day, in the not too distant future, we start to see real change and the gaps in Indigenous cancer prevention, diagnosis, treatment and control getting narrower and narrower.

Of course, each of our organisations and many individuals are already undertaking some fantastic and very positive initiatives. At the Peter MacCallum Cancer Centre, we have, as part of our deep commitment to Closing the Gap, developed dedicated clinical pathways in some cancers as well as supportive care models tailored to the unique needs of Indigenous patients.

We have prepared an Aboriginal and Torres Strait Islander Health Strategic Framework, which focuses on the pillars of care, research, employment and community engagement.

But we know we have a way to go, we know we have gaps, and we know we must work in partnership. We need to draw on the knowledge and expertise of others and share our knowledge to make a genuine and long-lasting impact on the health outcomes and wellbeing of Aboriginal and Torres Strait Islander peoples.

I thank you all for your commitment and, in advance, and for your very important contributions. On behalf of the Peter MacCallum Cancer Centre, I thank you for partnering with us and we look forward to the great things that will come from these, in many cases, new partnerships in cancer.

I now have the pleasure of introducing Dr Pradeep Phillip, the Secretary of the Department of Health.

Opening Address: Dr Pradeep Phillip

Secretary, Department of Health Victoria

This is a great collaborative initiative and it's a pleasure to be here. It is particularly good to see a focus on cancer by our brightest and best in such a concentrated fashion to improve the lives of some of our people.

Working together, through initiatives such as this Roundtable, increases our ability to address the complex issues affecting Aboriginal people and drive improvements in their health outcomes.

I would like to start by painting the landscape that we confront to remind ourselves of the key issues facing this Roundtable. Overall, Aboriginal people have a lower chance of surviving five years following a cancer diagnosis than non-Aboriginal people. The rate of new cases of cancer is higher for Aboriginal Australians than for other Australians and the cancer mortality rates are also around 1.5 times higher. This is the national picture but it is generally reflected here in Victoria.

Of concern is the fact that Aboriginal Australians experience higher rates of preventable cancers, i.e. those associated with modifiable risk factors. So the higher rate of certain risk factors in communities goes part way to explaining some of the observed cancer incidence and mortality patterns. This is truly a tragedy because it is something that we can actually do something about.

So, consider the following four observations:

- **1:** Aboriginal people aged 18 years and over are more than 1.5 times more likely to use tobacco than non-Aboriginal Victorians. And, not surprisingly, the data show that Aboriginal Australians are nearly twice (1.9 times) as likely to develop and die from lung cancer than other Australians.
- 2: Aboriginal populations carry a disproportionate burden for Hepatitis B and C infections both of which are associated with liver cancer. Aboriginal people are three times as likely to develop, and 3.3 times more likely to die from, liver cancer than other Australians.

- **3:** Aboriginal communities face complex barriers to participating in prevention and early-detection programs. This is reflected in lower participation rates in organised screening programs, resulting in an increased risk of late-stage disease at diagnosis. In 2014, to be in a situation where a cohort of our population in this case our Aboriginal and Torres Strait Islander peoples suffers so much ill-health because of the lack of screening and early detection, relative to the rest of the population, is appalling. These lower participation rates mean, for example, that Aboriginal women are 2.8 times as likely to develop cervical cancer and 3.9 times as likely to die from the disease, compared to other Australian women.
- **4:** But even after cancer is detected, it is no wonder that Aboriginal Australians suffer poorer outcomes when they are less likely to receive treatment than other Australians who present with the same condition. This is reflected in the national hospital admitted data collection, which shows that for the period 2006/2007 to 2010/2011, Aboriginal people were two-thirds less likely to be hospitalised for a principal diagnosis of cancer compared with other Australians.

What all these data highlight are the issues and gaps in cancer control for Aboriginal people across the entire system. The imperative for action is also clear. For all the funding and advances in cancer treatment and care, there is now no excuse for such a large gap to exist. Much work needs to be done, and some has already begun.

Here in Victoria, we are implementing a number of initiatives to address the cancer burden on Aboriginal Victorians, including the following:

 Koolin Balit (meaning 'healthy people' in the Boonwurrung language) is the Victorian Government's strategic directions for Aboriginal health over the next 10 years. Koolin Balit sets out what we, together with Aboriginal communities, other parts of government and service providers, will do to achieve the government's commitment to improving Aboriginal health. The strategy takes a life-

- cycle approach to health, with key enablers identified as improving data and evidence, strong Aboriginal organisations and cultural responsiveness. Cancer-related care is a critical priority across the spectrum of the work.
- Working Together for Health is a Koolin Balit initiative, and is a place-based and integrated approach to delivering culturally safe preventive health to Aboriginal Victorians. The focus areas are:
 - screening and cancer prevention
 - oral health
 - sexual health and viral hepatitis
 - tobacco.

Starting in the Loddon Mallee region of Victoria, this initiative will improve the way in which services work with each other:

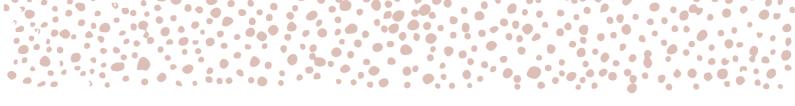
- to meet their Aboriginal patients' health needs
- to ensure our State-wide cancer prevention services and early-detection services prioritise Aboriginal health in the selected regions
- to ensure mainstream preventive health services are more welcoming, accessible and responsive to the local Aboriginal community's needs.

In addition, we will ensure that prevention is part of the core business of Aboriginal Community Controlled Health Organisations (ACCHOs) and we will support them to deliver innovative and culturally safe preventive health programs in the local Aboriginal community.

Closing the Gap... Properly

There are many specific initiatives and programs under the framework of *Koolin Balit* that are targeting specific issues related to the health needs of Aboriginal and Torres Strait islanders – with all of them working, though some more successfully than others, at helping to Close the Gap as part of our larger journey towards meaningful reconciliation.

So it is worth taking a moment to reflect on this great and important journey towards reconciliation that



we have been on for some years now. Critically, we need to remember that reconciliation is not merely a matter of programs, of dollars, or metrics and of figures. Ultimately, Closing the Gap is about people – about people relating to people.

At base, Closing the Gap, if we are to do it in a convincing and complete way, is about effecting a cultural change in our society and in our public consciousness. Without this cultural change, all the programs that might issue forth from eager governments will ultimately amount to relatively little.

And we have important signposts to remind us, at each and every stage, what our focus should be. We have the signpost of Mabo. We have the Ronald Wilson-led 1997 *Bringing them Home* based on the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families that Michael Lavarch established in 1995, but which had its precursor in the 1992 call for an Inquiry by the Secretariat of the National Aboriginal and Islander Child Care.

We have the powerful 1994 piece *Telling our Story* by the Aboriginal Legal Service of Western Australia with its interviews of around 600 people who had been deeply affected by the policy of removing Aboriginal children from their families. We have Tom Calma's 2005 *Social Justice Report* calling for governments to commit to achieving equality for Indigenous people in the areas of health and life expectancy within 25 years. This was, of course, the precursor to the Closing the Gap movement which now sees Prime Ministers of both major parties committed to a Parliamentary report every February on the progress made. And we have the National Apology to the Stolen Generations of 2008.

Each of these, and of course there are many others, are powerful reminders for us on the direction we must head; of not just the program we need to build equality but of the change in mindset that is required. And this criticality of cultural change is as important to Closing the Gap in health as in all other things. However, and as we all know, culture is an amorphous and difficult thing to influence...

particularly for those of us in health. For culture emerges from social sources far broader than those related solely to health.

But in the health context, we have confronted this problem. Our very best research tells us that if we want to improve the health of our populations, we must understand and intervene in the social determinants of health and ill-health. And the same is true for Closing the Gap – we must understand where the gap comes from in order to close it.

And we find that the gap comes not only from access or availability, but also from how people interact with our health system, how our system treats them, and how people see themselves in the context of our system – empowered or disempowered, active or passive?

For too long we have allowed all of our people, and particularly Aboriginal people, to be treated as passive users in our system, to be treated our way or not at all. This must change. This is the gap. Our system is for people. We must meet their needs, their expectations, their requirements – on their terms, not ours. Each of us in the health system must change if our system is to change, and our system must learn to welcome – with compassion – Aboriginal people as co-producers of their own health. And when we achieve this, then finally we will start to Close the Gap... properly.

The journey of this cultural change begins with conversations like the one we will all have today. I encourage you to recognise this – the great responsibility and the great challenge that we all have and that stands before us. For in remembering it, perhaps we shall be spurred on by ourselves and each other to achieve far more than any of us could alone. It is with great pleasure, great honour and great hope, that I open today's discussion. Thank you.

Day 1: Presentations and Discussions

Introduction: Professor Kerry Arabena

Chair of Indigenous Health, The University of Melbourne

Professor Arabena began by encouraging participants to collaborate, exchange information and knowledge to:

- · create opportunities for capacity building
- identify which resources raise awareness about, and the need for, cancer screening
- generate ideas about 'changing the narrative' around cancer so as to create a better understanding among Aboriginal people of the importance of screening and treatment.



VACCHO CEO Ms Jill Gallagher AO addresses the Rethinking Cancer, Raising Hope Roundtable

Discussions then took place about what a future cancer service might look like and the need for greater cultural awareness throughout the health sector. Not only would collaboration, partnerships and information be required but also increased opportunities for training to grow the number of Aboriginal people working in the health professions.

It was suggested that overcoming low cancer screening rates in Aboriginal communities could, in part, be addressed by encouraging mainstream health services and ACCHOs to develop partnership pathways to strategise in this area. Research priorities were also discussed with the aim of identifying gaps in research and the possible research strategies that need to be developed. Forward planning and mechanisms for coming together in the future were also discussed.

Presentation: Ms Jill Gallagher AO

CEO, Victorian Aboriginal Community Controlled Health Organisation

Ms Gallagher spoke of her 17 years working at the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), including 10 years as CEO, and also of her own cancer journey.

Ms Gallagher referred to VACCHO's challenges in this area, one of which is the need to engage more with cancer services, as currently they are not resourced to do this work. In the past VACCHO has had ad hoc meetings with cancer services, but has recently restructured and is now systematising this engagement through its Public Health and Research Unit.

I was diagnosed with bowel cancer at the age of 54. The year leading up to my diagnosis was really hectic, so I put feeling tired all the time down to working too hard and being busy. I noticed a change in my bowel habits but I always blamed it on something I'd eaten or a bug. It never occurred to me it could be anything more serious. My advice is, don't take the chance; if you notice anything unusual see your doctor immediately. And if you're 50 or over, don't wait for signs – there's a simple home test you can do that can find bowel cancer early. It could save your life.

- Jill Gallagher AO



There are challenges with the health system, including a lack of peer-support programs, and accessing the mainstream system can be daunting for Aboriginal and Torres Strait Islander people... Screening is not working as well as it should, which means that people often present with advanced disease that limits their treatment options... Mainstream systems might need to 'think outside the box' by using outreach services... Once gaps have been identified there needs to be commitment from government to work together to address this issue.

She also noted the need for a collaborative approach to primary and secondary health services to work together: for example, ACCHOs and hospitals developing better referral pathways and a joint understanding of the needs of patients.

Panel Discussion: Collaboration makes a difference

We have a commitment to developing a Cancer Action Plan for Victorian Communities with an emphasis on Closing the Gap for Aboriginal and Torres Strait Islander people living in Victoria.



Panel members (L–R): Ms Leanne Adams (Aboriginal Health Services Officer, Peter Mac), Ms Dale Fisher (CEO, Peter Mac), Professor Joan Cunningham (Menzies School of Health Research), Mr Jason King (CEO, VAHS), Mr Todd Harper (CEO, CCV), Ms Jill Gallagher AO (CEO, VACCHO)

Themes to be explored in the development of a Cancer Action Plan for Victoria

Key enablers

In creating a Cancer Action Plan for Victoria, we sought to identify key enablers other than those incorporated in the *Koolin Balit* strategy. Key messages from Roundtable participants included the following:

- A solid evidence base should be used to determine funding.
- Resources are needed to develop integrated service systems for target groups, particularly for under-screened populations.
- The development of community-based approaches to facilitate promotion of key messages.
- Establishing strong relationships and networks between cancer, hospital, Aboriginal and carer services with patients and families for message development, dissemination and sustainability of programs targeting at-risk populations.
- Any community member or practitioner in every service should be able both to impart and reinforce key cancer-related health messages to improve patients' understanding of their health, and of the health and wellbeing of their carers.
- Promoting the message that cancer is not a death sentence we need support to get that message out there.

What is already known on this subject

- Compared to other Australians, Aboriginal and Torres Strait Islander peoples receive less treatment for their cancer and have lower cancer survival rates.
- People living in rural and remote areas of Australia have poorer access to cancer treatment services and lower cancer survival rates compared to those in urban areas.
- The availability of outreach services, transport and accommodation for those travelling into the cities for treatment are likely to be part of the solution.
- Improving cancer outcomes for the general population such as establishing regional oncology centres of excellence and incentivising suitably qualified professionals to staff these centres, might also benefit Aboriginal Australians in these areas.
- Further research into how Indigenous cancerrelated outcomes vary according to the level of remoteness is urgently needed, in order to identify priority areas for action to improve cancer outcomes for Aboriginal Australians.⁶

Key messages: Screening, diagnosis and treatment

Optimal communication is essential to the delivery of effective and efficient cancer screening, diagnosis and treatment services. It is important to work out with individuals what they want to know and when, and how they want the service to respond.

Enablers for improving screening, diagnosis and treatment for Aboriginal and Torres Strait Islander peoples in Victoria can be broadly grouped into the following three inter-related concepts.

Diaz, A., Whop, L. J., Valery, P. C., Moore, S. P., Cunningham, J., Garvey, G. & Condon, J. R. 2015, 'Cancer outcomes for Aboriginal and Torres Strait Islander Australians in rural and remote areas', *Aust. J. Rural Health, Special Issue – Rural Cancer Review*, 23:4–18.

Individual and family case management

- Individual case management approaches are essential in creating a sense of familiarity and increasing the likelihood of individuals wanting to engage with services.
- Promoting options for people throughout the process of being screened, diagnosed and treated through positivist messages and strategies will facilitate appropriate knowledge transfer and provide support.
- Providing optimal support for individuals, particularly those with other conditions (e.g. mental health issues), who are vulnerable to homelessness and other social determinants that impact on patient care (e.g. poverty, transport issues, time management difficulties) and advocating for them within and between health services when necessary (e.g. with hospital services and specialist care).
- Personalising care plans and journeys for people – by tapping into the strong, nonmaterial incentive of Aboriginal people's own desire to be healthy, and by understanding the circumstances in which people live (e.g. offer appropriate nutritional advice based on income, circumstance and ability to prepare foods).
- Taking a 'trauma-informed' approach to the delivery of services – i.e., that a diagnosis of any kind, hospitalisation or engagement with services known to be racist have an adverse impact on the health and wellbeing of Aboriginal and Torres Strait Islander peoples. It is important to understand this and work with people in a way that recognises the trauma of a diagnosis, and the full impact of it for Aboriginal individuals.

Community-based approaches

- A visioning approach in which communities are empowered to take command of their future by developing how they want cancer screening, diagnosis and treatment services to be delivered on their terms.
- A peer-led approach identifying community people with established and credible standing who can endorse and support the desired health-seeking behaviours, and be influential in promoting early diagnosis, screening and treatment.
- Developing customised programs for Aboriginal people which operate on the basis that the community has inherent strengths and supports, thereby focusing on abilities not weaknesses.
- A participatory approach one that involves individuals, the family and the community context in which they live so that those interested get to have a voice in the support of individual patients.
- Services need to follow people back home, to their houses – this new emphasis on transitions between institutions and home communities is an essential area of work and is little understood or acted upon.
- Cancer services should be evaluated by universities and findings included in the peer-reviewed literature – this can then form the evidence base to incorporate into other jurisdictions and inform best practice.
- Programs that have been done well in the community should be examined for their effectiveness and capacity to be replicated across other jurisdictions.

My friend who has a lot of trauma about sexual assault was diagnosed with cervical cancer and has decided not to have treatment because the trauma has been reactivated, and she cannot stand the interaction with the doctors at the hospital: her journey, her decision.

Relationship and network development

It was discussed that relationship and network development were important aspects of community engagement, and that a multifaceted collaboration is required with various internal and external stakeholders at all levels – local, State and national. Stakeholders could be recognised leaders and local champions, or those directly involved and indirectly involved with health care provision. Therefore, it is necessary:

- To connect and engage with a wide range of stakeholders in the development of a Cancer Action Plan for Victoria, ensuring it is appropriate, relevant and capable of being implemented to effect necessary system changes.
- To have a coalition of organisations prepared to work together for cancer services in Victoria, similar to the 'Coalition of the Intentional'.⁷
- To establish a 'virtual community' to improve health and wellbeing, to drive advocacy and to influence commercial and political agendas.
- To engage community people and networks in the design of the physical infrastructure of cancer services, as well as in the development and delivery of effective cultural sensitivity training across all services in Victoria.
- To have good quality data to deliver good quality services – evidence of what works and linked data where necessary. Currently, the Victorian Cancer Registry at the Cancer Council Victoria (CCV) does not collect accurate enough information and the numbers are too small to be reliably counted.

 To be responsive to gender issues in our communities, and consider how men and women deal with things differently in relation to screening, diagnosis and treatment.

Benefits of collaboration

Creating a State-wide approach to ensuring the development and delivery of consistent, evidence-based strategies in this area is dependent on the strength of community engagement and collaboration between all levels of the health system. While this method of collaboration is a central tenet of working effectively in Aboriginal health, it may be challenging for mainstream cancer services to take an ecological approach to health and wellbeing (matching holistic concepts of Aboriginal health) for Aboriginal patients, which is different to the current services provided to mainstream populations.

It will also depend on the capacity of already overstretched services on the front line. Oftentimes, working effectively with patients and families is left to the Aboriginal Liaison Officers working in the hospital, but this is not a sustainable or an effective strategy because one person in a hospital system cannot be responsible for all Aboriginal patients – ALL professionals in a hospital must be culturally sensitive and aware.

Workshop participants then explored the benefits of working together in collaborations looking to support the uptake of cancer prevention, detection and treatment services with communities across

Mistakes have been made in the past by separating cancer from other chronic illnesses I know a patient who had to make a four-hour trip to see a doctor for 10 minutes about one condition then had to make the same trip the next week to deal with another condition. This woman had two children who needed to be looked after while she made the trip both ways – an additional burden on a family already experiencing hardship.

⁷ For more information on the 'Coalition of the Intentional', go to: http://vcoss.org.au/media-release/victorians-come-together-to-say-close-the-gap/.



This is an area in need of advocacy, a strong united voice. A lot of resources have been going into this area for a long time, but we are not seeing people get diagnosed early. Many are still leaving it until it is too late. We need a coordinated approach, we need to have an effective plan and we need to come together to be strong for those who are suffering. The system makes it unfair. It has been unfair for a long time.

- Workshop participant, Day 1

Victoria. There was a whole-of-Workshop participant agreement supporting the development of a Cancer Action Plan for Victoria with a particular emphasis on Aboriginal and Torres Strait Islander people. Through this process, participants wanted to see genuine partnerships and effective collaboration founded in principles consistent with those held by the National Health Leadership Forum.⁸

Closing the Gap through collaboration then requires formal agreements between agencies genuinely committed to:

- Sharing knowledge, leadership, training and opportunity in mutually beneficial ways.
- Ensuring a reduction in the duplication of effort and the wasting of resources.
- Having a secretariat or clearinghouse to ensure partnerships are continually up to date and informed of action.
- Partnering to improve sustainability, develop evidence and to promote sharing within and between institutions, practitioners and communities.

- Demonstrating improvements in the referral systems, linkages, patient-supported pathways and an increase in formal agreements between organisations to work together.
- Supporting cross-organisational processes developed for joint funding, advocacy and the uptake of service-delivery solutions.
- Translating evidence into practice and ensuring, where possible, it's peer reviewed and meaningful.
- Sharing resources to engage and educate individual patients, carers and health practitioners.
- Practising and promoting data linkage where possible and appropriate.
- Identifying where people 'fall in between services' – Including the issue of how to address 'non-compliance issues' among Aboriginal people who do not want to attend treatment – addressing these systemic issues will take a whole-of-services, whole-of-State approach.
- Addressing issues between urban, regional and remote area service delivery in the lead up to treatment and upon release from hospital.

To Close the Gap, to achieve equity for our people, we need longer than a two-year plan. We need a 10-year plan. We need to build capacity and health literacy in our organisations. We need to focus on ACCHOs doing the work well. We need to engage community... the best initiatives are the ones driven by Aboriginal people ourselves. We need to establish links between patients, oncology services and VACCHO. We need to stop non-compliant patients dropping down the list and become de-prioritised... we need to work together and we need to work together now.

⁸ For more on the National Health Leadership Forum, go to: www.naccho.org.au/aboriginal-health/national-congress-health-leadership/.

Day 2: Presentations and Discussions

Workshop 1: Reducing the risk of cancer

Ms Kylie Belling (CCV)

Cancer Council Victoria has developed resources (pamphlets and targeted interventions) focusing on tobacco action and Healthy Lifestyle Workers, and taken up social marketing (Facebook, twitter) in a mix of strategies used to raise awareness of the benefits of living a healthy lifestyle and quitting smoking. Ms Belling focused on popular campaigns that encourage people to consider quitting and that promote Quit Victoria within communities.

Additional resources included videos and posters that allay people's fears of calling Quitline for assistance and support. The Aboriginal program at Quit is a long-term investment, but there is a need for new messages that resonate with the community. There is also a need to try different approaches to reach target audiences, e.g. using comedy.

Gap analysis: Workshop 1

To reduce the risk of cancer in Koori communities there needs to be a focus on creating healthy lifestyles, including support to quit tobacco, addressing mental health and other issues such as stress, and encouraging people to seek early detection, diagnosis and treatment services for all cancers. Participants identified two broad areas where there were gaps in reducing the risks of cancer.

Health promotion

- Messages need to be developed in consultation with community people and relevant professional bodies.
- The continuing education of health care providers needs to be examined to ensure that health messages and strategies are consistent and evidence informed.
- Communities must be engaged in the dissemination of key messages.

- At all times, the method of delivering key messages needs to be founded on the principle of cultural safety.
- School-based education strategies could be more powerful if there were also messages for family members about the impact of smoking on children's health.
- Messages that promote positivity and community strength will have a longer lasting impact than those that focus on negatives and weaknesses.
- Successful Aboriginal-led programs could be promoted as national best practice strategies for all communities across Australia.
- There needs to be collaboration on a national level (e.g. Diabetes Australia, Heart Foundation and Cancer Australia) to develop and disseminate several clear messages about how to reduce the risks for cancer and chronic illness.

Workforce development

- Accreditation and professionalisation of Aboriginal Liaison Officers (ALOs) in the health workforce – need to be able to differentiate between the expertise and complexity attached to different roles so that they can be adequately renumerated.
- Workforce competencies have been developed for cancer workers in South Australia that could be taken up in Victoria.
- Health services need to work with health care providers to ensure data is accurate and used in service improvement strategies – data collection processes need to be standardised with an Aboriginal identifier.
- Health service delivery models need to provide outreach services – to address social determinants issues impacting on a patient's capacity to engage with cancer services, or to treat cancer within a chronic disease framework.



Workshop 2: Find cancer early

Ms Kate Broun (Papscreen Victoria)

The three Commonwealth-led national screening programs are in the areas of cervical, breast and bowel screening, all three of which see high rates of cancer among Aboriginal and Torres Strait Islander people. Most of the messages about these types of cancers are channeled through providers of mainstream screening. One Department of Health Victoria project has 290 nurses involved in routinely collecting information, so Papscreen Victoria is now able to report on that information.

This presentation highlights the importance of providing resources for community and practitioner education, such as mass media campaigns, and joint screening pilot projects. Although these projects show novel methods of engaging under-screened populations, they are not currently resourced well. For example, a joint screening service pilot in the Grampians region for BreastScreen, in which people were bussed to the site, screened and given information, was shown to work – but there is no funding available. Governments are, however, starting to look at alternative pathways, as they realise that one size does not fit all.

Gap analysis: Workshop 2

Workshop participants recommended that:

- Health promotion strategies for health care providers be developed collaboratively to ensure strong collective agreement and acceptance.
- Key messages are clear and consistent and existing message variations are overcome through consultation with all relevant professional bodies. This may require reexamination of workforce education both at basic educational and at professional levels, where best practice guidelines are produced and continuing education is provided.
- Screening tests in health services could be incentivised for practitioners and individuals.

- A peer-led approach is taken to building workforce knowledge and capacity, and to creating cultural shifts in perceptions of responsibilities, e.g. the role of the ALO.
- Community leaders and family members need to engage with extended families about how their lives are affected by a cancer diagnosis.
 Extended families are consulted about cancer prevention and education services and engagement with hospital liaison staff.
- The narrative of screening programs is changed to promote the benefits of early screening, e.g. 'Optimistic screening':) rather than 'Cervical screening programs': (
- Effective data collection and access by researchers be supported.
- Cancer Action Plans need to support the creation of seamless services from prevention to palliative care so as to meet real need and provide opportunities to reconceptualise services. This might mean enabling different evaluation frameworks, methods of community engagement and developing resources.

Workshop 3: Management and support during and after treatment

Ms Alison Hocking (Peter Mac), Ms Michelle Winters (SVHM) and Ms Leanne Adams (Peter Mac)

During treatment the following issues need to be addressed:

- Confidentiality and cultural safety.
- Rurality it's scary and dislocating to be in the city so a support person is needed (to hear and reinforce messages).
- Accommodation regional versus metropolitan services.
- Specialist versus generic services where can the treatment be delivered?
- Transport to access specialist and hospital care particularly for those in remote communities.

- Support people and coordination needed along with support for families (we look at the whole family system), which can be big – all of these people need different levels of information and support.
- Financial concerns economic burden of cancer can be great.
- Health literacy resonates throughout the course of treatment.
- Access to medications different to VAHS or GP service.
- Patients have presented with multi pre-morbid conditions including mental health issues.
 Some of these conditions may appear as a consequence of the cancer diagnosis.

After treatment the following issues need to be addressed:

- Specific support groups or culturally safe are needed by Aboriginal patients – how do we make general cancer support groups safe for all people who have had cancer?
- Patients lost to follow-up coordination between services is crucial, as is the lack of telehealth services
- Where distance is an issue, how do we skill up other clinicians to support patients rather than bringing them into the city?
- Complex medical management with other preexisting conditions – a need to work together.

Other gaps:

 Where are the Aboriginal patients? We just don't see Aboriginal patients in our service.
 Where are they going?

- We do not know where patients are getting referred from – need stronger referral base in Victoria.
- Lack of involvement by Aboriginal people in clinical trials – is this due to later stage presentation?
- Specialist cross-cultural training for oncology staff – is this required?
- Is there an educational module of cultural competency for Aboriginal people we could use or develop?

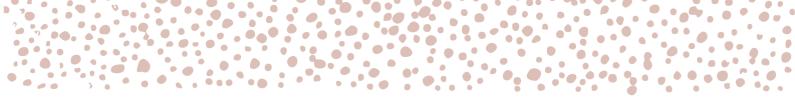
Gap analysis: Workshop 3

Workshop participants recommended that:

- We develop culturally appropriate models of care, and increase the options for choices of care.
- We support a centralised hub of cancer services to undertake the coordination of activities that benefit service providers and community people.
- We examine existing services for quality improvements in health care for further adaptation and ideas.
- We need to engage with patients appropriately

 not raise false hope or disempower people
 who lack knowledge of treatment processes
 and who might lack supportive care.
- We need to focus on building capacity for increased medication literacy and access to cancer services.
- We need to address the gap in information and resources about cancer for Aboriginal people.
- We need to be motivated by a patient's desired outcomes – care has to been seen as

We need to hook in with local services and we need to talk to VACCHO about patients. Wouldn't it be fantastic to hook patients in with local families, especially if they had to relocate from a regional area – an adoption system where patients could be adopted by a local family during their cancer journey...



Working with Aboriginal communities around death and dying is a whole new landscape; employers need to have systems that support the needs of Aboriginal workers in this field. The life-death-life cycle is evident in the holistic concept of Aboriginal health, and because of this we need to take a positive stance about the process of dying. Family is the primary unit of care and should be central to palliative care services. Where possible, we should attempt to respect the wishes of people who want to return to Country to die.

- Workshop participant, Day 2

integrated and timely (linked with primary and acute care).

• We need strategies to reduce the stress to families and individuals who 'do not know what is happening next'.

Workshop 4: Care and support at end of life

Ms Belinda Stevens (VACCHO)

Belinda gave an overview of VACCHO and the role of ACCHOs. She then focused on the concept of holistic health and what encompasses health and wellbeing for Aboriginal people. VACCHO has 27 member organisations across Victoria and their aim is to ensure that local communities are getting the services they require.

The Victorian Aboriginal Palliative Care Project (VAPCP) began in 2005 after receiving funding for 12 months from the Victorian Department of Health. VACCHO was then able to demonstrate the need for the project to be ongoing and VAPCP now receives recurrent funding.

The vision of VAPCP is to 'Create a sustainable and culturally safe palliative care service system where Aboriginal people from Victoria can access palliative care services in the setting of their choice'. The

project works to build positive relationships between palliative care consortiums and ACCHOs. To date, VACCHO has developed partnerships with Palliative Care Victoria and the Department of Health, which greatly facilitates State-wide initiatives.

Gap analysis: Workshop 4

Workshop participants recommended that:

- Care coordinators be based in ACCHOs to help individuals and families navigate within and between services. The gaps for this serviceenhancing initiative are resources, staffing, funding and training.
- Support groups designed by and for Aboriginal people be established and resourced.
- Aboriginal people have access to a legal referral service – e.g. CCV working on a pro bono legal service that is currently being piloted.
- Palliative care needs to be done really well as more Aboriginal people are in palliative care services than in treatment centres.
- Patients and families are experts in facing 'endof-life' and that they should be the starting point.

Appendix 1: Attendees at the Roundtable

Forty-five people from the following institutions participated in the Rethinking Cancer, Raising Hope Roundtable:

Onemda, The University of Melbourne

The University of Melbourne

The Lowitja Institute

South Australian Health and Medical Research Institute

Peter MacCallum Cancer Centre

Aboriginal Community Elders Services

Menzies School of Health Research

Cancer Council Victoria

Cancer Australia

NSW Cancer Institute

Victorian Aboriginal Community Controlled Health Organisation

Victorian Aboriginal Health Services

Victorian Department of Health

St Vincent's Hospital Melbourne

AFL SportsReady

CoHealth

Appendix 2: Rethinking Cancer, Raising Hope Roundtable Program



