

# World Indigenous Cancer Conference 2016

12-14 April 2016

Brisbane Convention and Exhibition Centre  
Queensland, Australia





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Parts of this report were derived from Marie McNerney and Melissa Sweet reporting on WICC 2016 for Croakey Conference News Service.

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For the purposes of this document, 'Indigenous' respectfully refers to Australia's Aboriginal and Torres Strait Islander peoples, and other Indigenous and tribal peoples from around the world.



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## 1. Executive Summary

Greater understanding of the burden of cancer among Indigenous populations is of major importance to public health given that poorer outcomes contribute to the lower life expectancies experienced by many Indigenous peoples. The inaugural World Indigenous Cancer Conference (WICC) was the first conference dedicated to focusing on cancer among Indigenous populations globally and attracted significant national and international interest.

Hosted by Menzies School of Health Research, in partnership with the International Agency for Research on Cancer, WICC 2016 was held at the Brisbane Convention and Exhibition Centre from 12 to 14 April 2016. WICC provided an unparalleled opportunity for representatives from the entire spectrum of the cancer control community to attend, including researchers, public health practitioners, clinicians, nurses, advocacy groups, allied health and other related professionals, as well as Indigenous community groups and leaders from around the globe.

A preconference workshop titled Racism and Health by David R Williams and Naomi Priest was held on 11 April 2016. The program also included three breakfast symposiums, a lunchtime seminar, and a mix of plenary and concurrent sessions. A Yarning Circle also ran over the three days, providing opportunities for delegates to share their cancer journey, stories, and programs from their respective countries and communities.

Overall, the conference was a success with 313 delegates from 15 countries registered to attend. Feedback during the conference was very positive and was also reflected in the post-conference evaluation survey. The theme of WICC 2016 was connecting, communicating, collaborating; highlighting the importance of supporting networks and continuing the momentum in translating the knowledge gained through research and practice to improve cancer outcomes for Indigenous people globally.

Delegates called for the establishment of an international Indigenous cancer network and supported a second World Indigenous Cancer Conference to be held in the next two to three years.





## 2. Conference Hosts

The World Indigenous Cancer Conference 2016 was hosted by Menzies School of Health Research, in partnership with the International Agency for Research on Cancer (IARC). WICC 2016 was supported by a Strategic Research Partnership Grant funded by Cancer Council New South Wales (STREP CaCIndA) and the Centre for Research Excellence in Discovering Indigenous Strategies to Improve Cancer Outcomes via Engagement, Research Translation, and Training (DISCOVER-TT). The conference was guided by an Executive Organising Committee and a Scientific Advisory Committee comprised of Indigenous and non-Indigenous members from Australia, Canada, New Zealand, USA, and France.

### Menzies School of Health Research

The Menzies School of Health Research is Australia's only medical research institute dedicated to improving Indigenous health and wellbeing. We have a 30-year history of scientific discovery and public health achievement. Menzies was established in 1985 as a body corporate of the Northern Territory Government under the Menzies Act 1985. This Act was amended in 2004 to formalise the relationship with Charles Darwin University (CDU). Menzies is now a major partner of CDU and constitutes a school within the University's Institute of Advanced Studies. Our work addresses critical issues such as mental health, nutrition, substance abuse, child health and development, as well as chronic diseases such as cancer, kidney disease and heart disease. We also lead global research into life-threatening illnesses in the Asia-Pacific, such as malaria and tuberculosis. We endeavour to break the cycle of disease and to reduce health inequities in Australia and the Asia-Pacific region, particularly for disadvantaged populations. Our mandate is to seek enduring solutions to problems that matter; the kind that when tackled, have the potential to make an immense difference to the quality of lives both here and abroad.



### International Agency for Research on Cancer

The International Agency for Research on Cancer (IARC) is the specialised cancer agency of the World Health Organisation. The objective of the IARC is to promote international collaboration in cancer research. The Agency is inter-disciplinary, bringing together skills in epidemiology, laboratory sciences and biostatistics to identify the causes of cancer so that preventive measures may be adopted and the burden of disease and associated suffering reduced. A significant feature of the IARC is its expertise in coordinating research across countries and organizations; its independent role as an international organization facilitates this activity. The Agency has a particular interest in conducting research in low and middle-income countries through partnerships and collaborations with researchers in these regions.



### 3. Why did we hold WICC?

For more than 30 years Menzies School of Health Research has been partnering with Indigenous communities and disadvantaged populations across our region to improve health outcomes and reduce health inequity. Through a commitment to excellence in research, the development of evidence-based programs and the fostering of local capacity through training and employment, Menzies is tackling significant Indigenous health issues, including cancer. Cancer in Indigenous populations globally has largely been overlooked, despite evidence that Indigenous people in some areas have significantly greater mortality and lower cancer survival rates.

Greater understanding of the burden of cancer among Indigenous populations is of major importance to public health given that poorer outcomes contribute to the lower life expectancies experienced by many Indigenous peoples. In efforts to reduce the burden of cancer affecting Indigenous peoples around the world, effective cancer control planning requires comparable and accurate local data. The International Agency for Research on Cancer (IARC) is the reference source in the development and dissemination of quality-assured global cancer indicators, and the Agency leads the implementation and advancement of cancer registration worldwide through the Global Initiative for Cancer Registry Development (GICR). With the WICC, IARC naturally developed a partnership with Menzies in the context of data for action and a platform to better understand and overcome the challenges to obtaining valid and timely cancer data on Indigenous populations. By bringing together Indigenous groups, researchers and governments, the WICC raised awareness of the need to detect disparities within populations at the global level to drive improvements in public health provision.

The inaugural WICC was the first conference dedicated to focusing on cancer among Indigenous populations globally and attracted significant national and international interest. WICC provided an invaluable opportunity for Menzies and WICC delegates to network and build partnerships with researchers, public health practitioners, clinicians, nurses, advocacy groups, allied health and other related professionals, and Indigenous community groups and leaders from around the globe. It also provided a platform to actively promote the translation of research knowledge into Australian public health policy and practice.





## 4. Conference Committees

### WICC Executive Organising Committee

Assoc Prof Gail Garvey (Chair)

Dr Freddie Bray

Prof Joan Cunningham

Dr Bronwyn Morris

Dr Suzanne Moore

Mr Noel Matson

Mr Brian Arley

Mr Matthew Plant

Ms Alana Gall

Ms Georgina Smart

### Scientific Advisory Committee

Prof Joan Cunningham (Australia) – Co-chair

Dr Suzanne Moore (Australia) – Co-chair

Dr Bronwyn Morris (Australia)

Prof Ian Olver (Australia)

Prof Dianne O'Connell (Australia)

Dr Isabelle Soerjomataram (France)

Prof Diana Sarfati (New Zealand)

Dr Brenda Elias (Canada)

Dr Angeline Letendre (Canada)

Dr Linda Burhansstiponov (USA)





## 5. WICC Sponsors

### FOUNDATION SPONSOR



### PATRON SPONSOR



### MAJOR SPONSOR



### SPONSORS



### CONFERENCE APP



### YARNING CIRCLE SPONSOR



### SUPPORTERS





## 6. Program

A Welcome to Country was given by Uncle Joe Kirk. He also discussed how we can all try to do better and work together to improve health outcomes for Indigenous people around the world.

The three-day program was a mix of plenary and concurrent sessions.



## TUESDAY 12 APRIL

07:00 - 09:00	CONFERENCE REGISTRATION
Auditorium Foyer	
09:00 - 11:00	OPENING CEREMONY + PLENARY ONE
Auditorium	
09:00 - 11:00	PLENARY ONE
Auditorium	<b>Why are we talking about cancer and Indigenous people?</b>
11:00 - 11:30	MORNING TEA
11:30 - 13:00	CONCURRENT SESSION 1
Room B1	<b>1.1 Epidemiology 1</b>
11:30 - 13:00	CONCURRENT SESSION 1
Room B2	<b>1.3 Poster &amp; mini-oral session</b>
11:30 - 13:00	CONCURRENT SESSION 1
Auditorium	<b>1.2 Leadership &amp; Partnership</b>
13:00 - 14:00	LUNCH
14:00 - 15:30	PLENARY TWO
Auditorium	<b>Screening &amp; prevention, early detection</b>
15:30 - 16:00	AFTERNOON TEA
16:00 - 17:30	CONCURRENT SESSION 2
Room B1	<b>2.1 Screening 1</b>
16:00 - 17:30	CONCURRENT SESSION 2
Room B2	<b>2.2 Palliative care</b>
16:00 - 17:30	CONCURRENT SESSION 2
Auditorium	<b>2.3 Resource &amp; program development</b>
17:30 - 19:30	WELCOME RECEPTION
Auditorium Foyer	

## WEDNESDAY 13 APRIL

07:00 - 08:00	GUIDED MORNING WALKING & RUNNING GROUPS
07:00 - 08:30	EARLY MORNING SYMPOSIUM 1 - Ticketed Event   Light breakfast provided
Room B1	
07:00 - 08:30	EARLY MORNING SYMPOSIUM 2 - Ticketed Event   Light breakfast provided
Room B2	
09:00 - 10:30	PLENARY THREE
Auditorium	<b>Engaging with communities and patients</b>
10:30 - 11:00	MORNING TEA
11:00 - 12:30	CONCURRENT SESSION 3
Room B1	<b>3.1 Methods</b>
11:00 - 12:30	CONCURRENT SESSION 3
Auditorium	<b>3.2 Psychosocial care</b>



## WEDNESDAY 13 APRIL (CONT.)

11:00 - 12:30 Room B2	CONCURRENT SESSION 3 <b>3.3 Resource &amp; program development 2</b>
12:30 - 13:30	LUNCH
12:30 - 13:30	SPECIAL LUNCHTIME SEMINAR – Ticketed Event   Lunch provided Hosted by Cancer Australia
13:30 - 15:00 Auditorium	PLENARY FOUR <b>Diagnosis &amp; care</b>
15:00 - 15:30	AFTERNOON TEA
15:30 - 17:00 Auditorium	CONCURRENT SESSION 4 <b>4.1 Treatment 1</b>
15:30 - 17:00 Room B1	CONCURRENT SESSION 4 <b>4.2 Leadership &amp; partnership 2</b>
15:30 - 17:00 Room B2	CONCURRENT SESSION 4 <b>4.3 Education &amp; training</b>
19:00 - 22:00 Sky Terrace BCEC	QUEENSLAND HEALTH GALA DINNER - Ticketed Event <b>Special Performance by Mr Archie Roach</b>

## THURSDAY 14 APRIL

07:00 - 08:30	EARLY MORNING SYMPOSIUM - Ticketed Event   Light breakfast provided
09:00 - 10:30 Auditorium	PLENARY FIVE <b>Wellness &amp; Survivorship</b>
10:30 - 11:00	MORNING TEA
11:00 - 12:30 Room B1	CONCURRENT SESSION 5 <b>5.1 Epidemiology 2</b>
11:00 - 12:30 Auditorium	CONCURRENT SESSION 5 <b>5.2 Consumer Voices</b>
11:00 - 12:30 Room B2	CONCURRENT SESSION 5 <b>5.3 Screening 2</b>
12:30 - 13:30	LUNCH
13:30 - 15:00 Room B1	CONCURRENT SESSION 6 <b>6.1 Risk factors</b>
13:30 - 15:00 Auditorium	CONCURRENT SESSION 6 <b>6.2 Strategies and frameworks</b>
13:30 - 15:00 Room B2	CONCURRENT SESSION 6 <b>6.3 Treatment 2</b>
15:00 - 15:30	AFTERNOON TEA
15:30 - 17:00 Auditorium	PLENARY SIX + FAREWELL <b>Priorities moving forward</b>
17:00	CONFERENCE CONCLUDES <b>Special Performance by William Barton &amp; Delmae Barton</b>











## 6.1 Program extras available during WICC 2016

- Pre-conference workshop – “Racism and Health Workshop: Learnings for Cancer” – facilitated by Professor David R Williams, Harvard University USA and Dr Naomi Priest, Australian National University, Australia (event reached full capacity with 50 delegates)
- Cancer Australia Lunch (event reached full capacity with 106 delegates)
- Welcome Reception and Queensland Health Gala Dinner (event reached full capacity)
- Breakfast symposiums:
  - Indigenous tobacco smoking and cancer prevention (92 delegates)
  - The renewal of the national cervical screening program in Australia (81 delegates)
  - With and for First Nations, Inuit and Metis (76 delegates)
- Dedicated Yarning Circle which ran its own dedicated program (see page 13 for details)
- Artist booth where local Indigenous artists sold their artwork

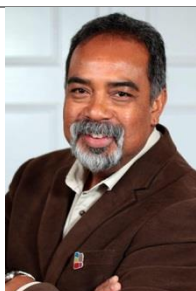
## 7. Keynote Speakers

A number of eminent international and Australian keynote speakers presented at WICC 2016.

 <p>Dr Freddie Bray <i>International Agency for Research on Cancer, France</i></p>	 <p>Dr Julia Brotherton <i>Victorian Cytology Service, Australia</i></p>	 <p>Dr Linda Burhansstipanov <i>Native American Cancer Research, United States of America</i></p>	 <p>Professor Tom Calma AO <i>Tackling Indigenous Smoking, Australia</i></p>
 <p>Assoc Professor Nadine Caron <i>University of Northern British Columbia, Canada</i></p>	 <p>Assoc Professor Gail Garvey <i>Menzies School of Health Research, Australia</i></p>	 <p>Assoc Professor Lou Irving <i>Royal Melbourne Hospital; Peter MacCallum Cancer Centr, Australia</i></p>	 <p>Dr Alexandra King <i>Royal College of Physicians of Canada</i></p>



Dr Angeline Letendre  
*Alberta Health Services, Canada*



Mr Romlie Mokak  
*The Lowitja Institute, Australia*



Ms Leanne Pilkington  
*BreastScreen WA, Australia*



Mr Archie Roach  
*Singer/Songwriter and Cancer Survivor, Australia*



Dr Judith Salmon Kaur  
*Mayo Clinic Comprehensive Cancer Center, USA*



Professor Diana Sarfati  
*University of Otago, New Zealand*



Dr John Waldon  
*2Tama Limited, New Zealand*



Ms Lisa Whop  
*Menzies School of Health Research, Australia*



Dr Chris Wild  
*International Agency for Research on Cancer, France*



Professor David R Williams  
*Harvard University, USA*



Professor Patsy Yates  
*Queensland University of Technology, Australia*



Professor Helen Zorbas AO  
*Cancer Australia, Australia*



## 8. Yarning Circle

The WICC 2016 Yarning Circle was a relaxed and welcoming space where conference participants listened to others and shared stories. Aunty Marg Lawton performed the Welcome to Country and invited people to participate in the Yarning Circle. This space provided the opportunity to connect people, and the stories told provided inspiration through discussions on cancer survival, cancer care and screening services, health and wellbeing programs, cancer research and education programs for Indigenous people internationally.

The three-day Yarning Circle program was developed by an Indigenous Australian advisory group comprising National Indigenous Cancer Network Ambassadors, Indigenous Australian community-controlled health services and peak organisations, research centres/institutions, and the Queensland Government along with partners from our global network of Indigenous cancer experts.



Participants hold the message stick and share their stories in the Yarning Circle

The Yarning Circle ran throughout the conference and delegates were welcome to yarn with Indigenous people and attend key discussions taking place in the breaks of the conference program.

The Yarning Circle was a popular space during the conference, situated in the central area between the auditorium and concurrent session rooms. Each day, Elders like Reg and Rose Crowshoe and Jerome Yellowdirt, First Nations people from Canada, would arrive early and take their places on the seats around the circle, alongside Aboriginal cancer ambassadors Aunty Marg Lawton and Uncle Bill Buchanan, and many others representing Maoris, Native Americans,

and Canadian First Nation, Inuit and Metis people.

We received a number of comments throughout the conference and in the post-conference survey about the value of the Yarning Circle.



The Yarning Circle in action at WICC 2016



## 9. Delegates

313 delegates registered to attend WICC 2016. These delegates were from 15 different countries, predominantly from Australia, New Zealand, Canada, United States, United Kingdom and India.

WICC 2016 was supported by 49 volunteers who dedicated their time to welcoming delegates, assisting speakers upload their presentations, assisting chairs to prepare their sessions, arranging flowers for the gala dinner and ushering delegates to sessions. Their contribution was invaluable.

## 10. WICC Entertainment

Art and music were a big focus at the conference, both in research presented about the role of both in therapy and also as a celebration. Delegates saw the Aboriginal dance group Nunukul Yuggera and the Malu Kiai Mura Buai dancers from the Torres Strait, as well as legendary Indigenous Australian singer songwriter Archie Roach, as well as performer, composer and didgeridoo star William Barton and his mum, “Dreamtime Opera Diva”, Aunty Delmae Barton. The majority of respondents in the evaluation survey (described later in this report) indicated that they enjoyed the entertainment and performances at the conference.

Malu Kiai Mura Buai Dancers at the Welcome Reception



Archie Roach at the Conference Gala Dinner



## 11. WICC Presentations



A major focus of WICC 2016 was the experiences of consumers and carers, and how they can contribute to the prevention, diagnosis, and treatment process.

Six plenaries and eighteen concurrent sessions, and a complimenting Yarning Circle Program, were delivered over three action packed days. The presentations reflected the broad range of delegates' experiences and backgrounds, with many people commenting that the mix of perspectives provided a richness not often found at conferences.

### 11. 1 Selected Program Highlights

Marie McNerney and Melissa Sweet were commissioned to report on program highlights through Croakey Conference News Service. The Croakey Conference News Service provides skilled, independent reporting of conferences (<https://croakey.org/conference-reporting/>). The following highlights are excerpts from the Croakey report, in addition to notes provided by the Chair of each plenary and concurrent session.

#### ❖ Racism in Health

Professor David R Williams (Harvard University, USA) and Dr Naomi Priest (Australian National University, Australia) presented a wide-ranging and illuminating workshop on racism and health. They discussed the multiple ways in which racism influences health and health inequalities, with particular implications for Indigenous cancer research, policy and practice. They also looked to evidence regarding promising interventions to reduce racism and its harmful effects.

One particularly interesting focus was on unconscious discrimination, or implicit bias as it's also known. As an illustration of implicit bias, Professor Williams told the workshop about a collection of words known as the Bound Encoding of the Aggregate Language Environment (BEAGLE), which contains about 10 million words sampled from books, newspaper and magazine articles as a representation of American culture. Researchers had interrogated the list to see what words went with others, and they found entrenched negative levels of stereotyping, particularly of black Americans.

Dr Priest, a Fellow at the Australian National University and Visiting Scientist at Harvard, outlined Reconciliation Australia research that showed similar stereotyping of Aboriginal and Torres Strait Islander people. Professor Williams said these stereotypes have "profound implications" for the way people see the world around them, from police officers regarding young black Americans as "dangerous" through to how health professionals make decisions. The typical clinical encounter, under pressure and with the need often to make snap judgements, "embeds conditions that maximise implicit bias," he said. Professor Williams said he makes a point of telling his students to expect that he is prejudiced in some way. "All of us have embedded in our minds, images and messages we have gotten as a result of being raised in a particular place at a particular time," Professor Williams said.

#### ❖ Cervical Screening in Indigenous Women

A landmark study published during the conference showed two-thirds of Indigenous women have not had a Pap smear, and that Indigenous women's screening rates in Queensland have not improved in the 25 years of the National Cervical Screening Program (NCSP).



Researchers from the Menzies School of Health Research commented that the NCSP has been “failing” Indigenous women, who are twice as likely to develop cervical cancer and four times more likely to die from it than other Australian women. While researchers have long suspected poor screening rates for Indigenous women – sadly because the mortality rates are so high – they haven’t had concrete evidence because pathology report forms, the main data source for the Pap smear register, do not identify if women are Indigenous.

To fill that gap, Professor John Condon led a retrospective cohort study of population-based linked health records for 1.3 million female Queensland residents aged 20–69 years who had one or more Pap smears during 2000–2011. From linked hospital records, 26,800 were identified as Indigenous women. Ms Lisa Whop conducted the initial analysis while completing her PhD. These results confirmed the fears: that two-thirds of Indigenous women don’t screen, and there had been no improvement in screening rates for Indigenous women in Queensland in the 25 years of the NCSP. The findings were published in the international journal, *Cancer*.

The study found that screening rates were particularly low for Indigenous women aged 45-49, the age range where cervical cancer is most likely to be diagnosed. Cervical cancer is largely preventable through screening with Pap tests, available to all Australian women aged 20 to 69 years through the NCSP. Ms Whop told the conference that since the NCSP began, cervical cancer incidence and deaths have fallen by over 50 per cent and Australian rates are now among the lowest in the world. But she said Indigenous women have not shared in those successes.

A parallel study by Ms Whop and colleagues was also published in the journal PLOS ONE, and reported that Indigenous women in Queensland are experiencing markedly higher rates of cervical abnormalities than non-Indigenous women. The study found that they are more than twice as likely to have a high grade abnormality as a non-Indigenous woman when they do present for cervical screening.

#### ❖ **Native Sisters – patient navigation for American Indian cancer patients**

In Colorado and other states in the US, a community-driven initiative is helping American Indian cancer patients to navigate a complex and confusing health system. The Native Sisters initiative arose out of a meeting some decades ago between Native American Cancer Research Corporation director Dr Linda Burhansstipanov and a renowned Harlem oncologist Dr Harold Freeman, who pioneered the patient navigation concept in 1990.

Dr Burhansstipanov had come to health via work in family violence and HIV/AIDs, and was inspired by the concept of patient navigation that Freeman founded after despairing of how sick so many black Americans were before they sought medical care for cancer. A Cherokee woman, Dr Burhansstipanov decided to return to her community and to set up a not for profit American Indian community version of the concept, and the Native Sisters were born.

“They do everything,” she said after presenting on the model to the World Indigenous Cancer Conference. “Our navigators work through the whole continuum of cancer care.”

Unlike many other liaison officers, the Native Sisters “cross the threshold of the clinical setting,” and get patients signed up for screening, and follow up on tests. They speak on their behalf if they’re having symptoms that they don’t know how to explain.

The Native Sisters help schedule and maintain clinical appointments, sit in on doctor visits to translate or help pose or answer questions, and, often, guide clinical staff on spiritual and native language issues.

“Every barrier we have identified, we have found that the navigator is successful at overcoming in a very respectful way,” she said.



It's a model that may hold promise in Australia, particularly in the wake of studies presented at the conference about the unmet needs of Indigenous cancer patients and the need for a bigger and more specialised Aboriginal health workforce.

Dr Burhansstipanov describes the case of one patient, who had become distressed while attending a health appointment. A Native Sister was called in and was able to find out that pictures of owls, used by the institution to show directions, was a symbol of death in her tribe. After that, the Native Sister led her into the building by a back way. For others, it's about providing a support to work through the mistrust many American Indians have of a medical system that abused them in the not so distant past: forced sterilisation, being lied to about what tests were being undertaken, and specimens shared without consent.

### ❖ **Cancer Survivor Stories**

One of the highlights of the inaugural WICC 2016 was a discussion between legendary singer Archie Roach and his doctor Associate Professor Louis Irving about Archie's recovery from lung cancer.

The packed auditorium was hushed through the hour-long conversation on the aftermath of the 2011 diagnosis that hit Archie while he was grieving the very recent loss of his long time musical and life partner, Ruby Hunter, who died aged just 54. They had been together for 38 years.

Their conversation conveyed a very respectful, two-way patient-doctor relationship and also reflected many of the issues that arose over the three days of the conference, including disparities in cancer incidence, treatment and outcomes for Indigenous people across the world. Like the conference, their conversation also shone a light on some of the underlying issues behind the grim statistics, including the impact of trauma and racism on health, and the experience of Indigenous peoples in unequal access to and treatment in the health system, and the different expectations they can end up having as a result about health and care.

Associate Professor Irving told a story about how Archie's older sister had come to visit him in hospital, but he had been moved to another bed. Asking to be shown where he now was, the nurse led the sister to an Indian patient. It was surely an honest mistake, Irving said, but told Archie he wanted to raise it "in the context of prejudice and not understanding people from different ethnicities". Archie said he didn't come across prejudice that much in hospital himself, but his concern was what happens to other Aboriginal people who don't have his profile. "I think if I'd just come in from the bush, would I get the same treatment, the royal treatment so to speak? "I don't think so. Sometimes I'm afforded the type of treatment I get because of my name, but my countrymen are not afforded the same respect."

The night before his Plenary presentation, Archie performed at the conference gala dinner. Elders nodded in recognition as Archie talked about being taken away from his family as a three-year-old, off the Framlingham mission on Gunditjmara country in southwest Victoria, of living on the streets for many years and his struggles with alcohol and the law.

You think you get through the trauma, he told them. And then comes cancer – and the added blow of a stroke. "It makes you sick," he said, before singing 'Took the children away', a song he said he never tires of performing: "It's my healing. Every time I sing it, it lets a little bit go."

As one delegate said: "He put the whole conference into song".

In another presentation, Aunty Robin Payne, an Aboriginal woman from Dubbo and a cancer survivor, discussed her road to recovery after a difficult pathway. Her big concern is how reluctant many Aboriginal women are to have a mammogram – "it's because of the white doctors, stems back to the Stolen Generations, a lot are frightened," she said. Growing up as one of the few Aboriginal families in a regional town, she says she doesn't share that concern about interacting with mainstream medicine, but it's left its mark nonetheless.

Ryan Pieters, a young Indigenous man from NSW who was diagnosed with cancer as a child, told a story of resilience and strength. He is now a medical student and emphasised that the struggles he endured early in life led him to the journey he is on and he discussed his aspirations to help Indigenous people once he has completed his studies.



#### ❖ **Wellness in the context of illness**

Dr Alexandra King's plenary session focussed on wellness, during which she discussed her work with Indigenous people in Canada and hepatitis C. She discussed how Indigenous Peoples aspire to wellness – a holistic journey of balance and connectivity; and how Hepatitis C is sometimes described as a spiritual wound. Integral to its social construct are colonialism, stigma and disruption. Dr King stated that achieving wellness in the context of hepatitis C demonstrates resiliency, transformation and self-determination, analogous to our wellness journeys as Indigenous Peoples, communities and nations. She has found that wellness was perceived as a balance of health in the physical, mental, emotional and spiritual dimensions of the individual. Wellness extends even further into the social, family, community and ancestral (past & future) domains of one's existence. Moreover, wellness was viewed as a journey, not merely a destination or an endpoint to be reached.

#### ❖ **Smoking and Lung Cancer**

Lung cancer is one of the most common cancers in Indigenous populations, according to the first ever comparative population-based study of cancer incidence in Indigenous people in Australia, New Zealand, Canada, and the United States.

Led by Australian researcher Dr Suzanne Moore, of the Menzies School of Health Research, it found that smoking is more common in Indigenous communities in all four countries than in their non-Indigenous counterparts.

Another keynote speaker, Professor Tom Calma talked about the success and challenges of the Tackling Indigenous Smoking initiative, which has seen significant success over the years but will, he said, fail to meet its target to have halved Indigenous smoking by 2018 because of “stop start” government policies that cut \$30 million from its work in recent years.

#### ❖ **Services and Programs that are working**

BreastScreenWA's mobile screening unit travels through remote Western Australian and has been boosting screening rates in remote Indigenous communities. Ms Leanne Pilkington reported that encouraging and implementing breast cancer screening among Aboriginal women, especially in rural areas, requires considerable flexibility, consideration of unique circumstances, and focus on the needs of the women.

In New Zealand Mr Wayne Borrell discussed focusing and engaging Maori men via family, physical, mental & spiritual health through a stand tall framework.

The National Indigenous Cancer Network (NICaN) was presented by Mr Brian Arley and Mr Matthew Plant as a means of community empowerment and engagement, communication, and collaboration with the aim to increase access to information about cancer for Indigenous people.





### ❖ Comorbidities of cancer

A New Zealand study that aims to look at how and why cancer patients miss out on curative treatment because they also suffer other chronic conditions, such as diabetes, could help to address higher cancer death rates among Indigenous people.

New Zealand cancer researcher Professor Diana Sarfati reported that there was growing international understanding that many cancer patients with comorbidities were being “under-treated”. This has major implications for Indigenous populations, including in New Zealand where the death rates from cancer are nearly twice as high for Māori compared with the rest of the population. With those studies in mind, Professor Sarfati’s team is set to do significant new research on comorbidity and is now recruiting patients for a feasibility study that aims to “de-silo” cancer care.

The study, which she said is breaking new ground, will test whether it’s feasible to look at the identification and treatment of comorbidity within acute cancer settings in New Zealand for patients with bowel cancer. They will look across four main domains:

1. assessment and active management of comorbidity, such as keeping unstable diabetes under control
2. assessment and management of polypharmacy, to see if medication reduction can reduce the risk of toxicity from chemotherapy
3. evaluation of mental health, with a particular focus on depression, given strong evidence that people with depression are less likely to take up chemotherapy
4. review of functional and psychosocial issues that might get in the way of treatment.

### ❖ Priorities moving forward

A breakfast session during WICC presented a discussion from The Canadian Partnership Against Cancer. This important partnership is improving First Nations, Inuit and Métis cancer control with and for First Nations, Inuit and Métis peoples and partners, through connections, communication, collaboration and implementation of the National Aboriginal Organizations Caucus, which includes the Métis National Council, Inuit Tapiriit Kanatami and the Assembly of First Nations. A model was presented for sharing and advancing the cancer control priorities of Indigenous populations at a national level and current initiatives were shared during the session.

Mr Romlie Mokak asked Australian delegates to consider “how we are travelling now”, in a political environment that has seen cuts to Indigenous health funding, a loss of Indigenous organisations, the mainstreaming and privatisation of health, and a focus on acute care and away from primary care and prevention. He also talked about the role of Indigenous-led research organisations like the Lowitja Institute.

“Part of this is about the creation of a space, where our people can come together and unapologetically say this is a black space, this is an Indigenous space, and we’re going to have the difficult yarns we need to have.”

Professor Helen Zorbas spoke about the importance of working under a model of engagement, where Cancer Australia’s work is informed by Aboriginal and Torres Strait Islander experts and community members to develop and deliver relevant, culturally appropriate programs. The development of a national cancer framework, engaging Menzies School of Health Research, used an evidence based, collaborative and consultative approach. Not only was a national cancer framework developed, but importantly, the process achieved a critical outcome: a shared owned agenda for improving Indigenous cancer outcomes in Australia.

Whether through systems change, knowledge or behaviour change...it’s all our responsibility.



## 12. Media

Over the duration of the World Indigenous Cancer Conference a number of media releases were sent to garner attention. From that we gained online, radio, and television media coverage.

### Online news sources

- ABC news – Cervical cancer screening rates among Indigenous women show no improvement: study  
[www.abc.net.au/news/2016-04-12/cervical-cancer-screening-rates-among-indigenous-women-low/7320974](http://www.abc.net.au/news/2016-04-12/cervical-cancer-screening-rates-among-indigenous-women-low/7320974)
- HealthInfoNet post – First ever world Indigenous cancer conference comes to Brisbane  
[www.healthinfonet.ecu.edu.au/about/news/4028](http://www.healthinfonet.ecu.edu.au/about/news/4028)
- SBS news – Indigenous cancer stats worse than thought  
[www.sbs.com.au/news/article/2016/04/11/indigenous-cancer-stats-worse-thought](http://www.sbs.com.au/news/article/2016/04/11/indigenous-cancer-stats-worse-thought)
- Croakey social journalism for health – Previewing the World Indigenous Cancer Conference, happening in Brisbane this week  
<https://croakey.org/previewing-the-world-indigenous-cancer-conference-happening-in-brisbane-this-week/>



Organising Committee Chair, Gail Garvey is interviewed by ABC News Brisbane

### TV coverage

- ABC News Brisbane: Researchers are concerned about the low rates of cervical cancer screening among Indigenous women (2 mins 03 secs)  
Interviewees: Ms Lisa Whop (Menzies), Associate Professor Gail Garvey (Menzies), Ms Kalinda Griffiths (University of Sydney) and Dr Julia Brotherton (HPV Vaccination Program)
- ABC News Darwin: Researchers are concerned about the low rates of cervical cancer screening among Indigenous women (2 mins 02 secs)  
Interviewees: Ms Lisa Whop (Menzies), Associate Professor Gail Garvey (Menzies), Ms Kalinda Griffiths (University of Sydney) and Dr Julia Brotherton (HPV Vaccination Program)
- The Point, NITV: Health experts have gathered in Brisbane for the first World Indigenous Cancer Conference (3 mins 25 secs)  
Interviewees: Professor David R Williams (Harvard University) and Dr Suzanne Moore (Menzies)
- ABC News 24: Researchers are concerned about the low rate of cervical cancer screening among Indigenous women (1 mins 57 secs)  
Interviewees: Ms Lisa Whop (Menzies), Associate Professor Gail Garvey (Menzies), Ms Kalinda Griffiths (University of Sydney) and Dr Julia Brotherton (HPV Vaccination Program)



## Radio coverage

- CAAMA Radio: Interview with Dr Suzanne Moore (Menzies School of Health Research) (9 mins 37 secs)
- Radio National, Canberra: Penny Timms' (newsreader) report about cervical cancer screening for Indigenous women from Ms Lisa Whop's (Menzies School of Health Research) research (2 mins 43 secs)
- 4K1G, Townsville: Wyles (newsreader) says that Indigenous communities, consumers and health experts will come together for the opening of the inaugural World Indigenous Cancer Conference (1 min 19 secs)
- 2MCE Radio News: Interview with Dr Suzanne Moore (Menzies School of Health Research) (0 mins 50 secs)
- 2MCE Radio News: Interview with Dr Suzanne Moore (0 mins 52 secs)

## Special coverage

- Indigistream interviewed WICC delegates and presenters. The interviews can be viewed [www.indigistream.com.au](http://www.indigistream.com.au)
- Croakey's coverage of WICC and Periscope interviews can be viewed <https://croakey.org/watch-some-interviews-and-stories-from-the-world-indigenous-cancer-conference/>



Lisa Whop, from Menzies School of Health Research, interviewed by ABC News Brisbane



## 13. Social Media

WICC had strong twitter engagement during the conference with 3,149 tweets generating over 10 million impressions.

### #WICC2016 Participants



### The Numbers

10,570,294 Impressions

3,149 Tweets

600 Participants

8 Avg Tweets/Hour

5 Avg Tweets/Participant

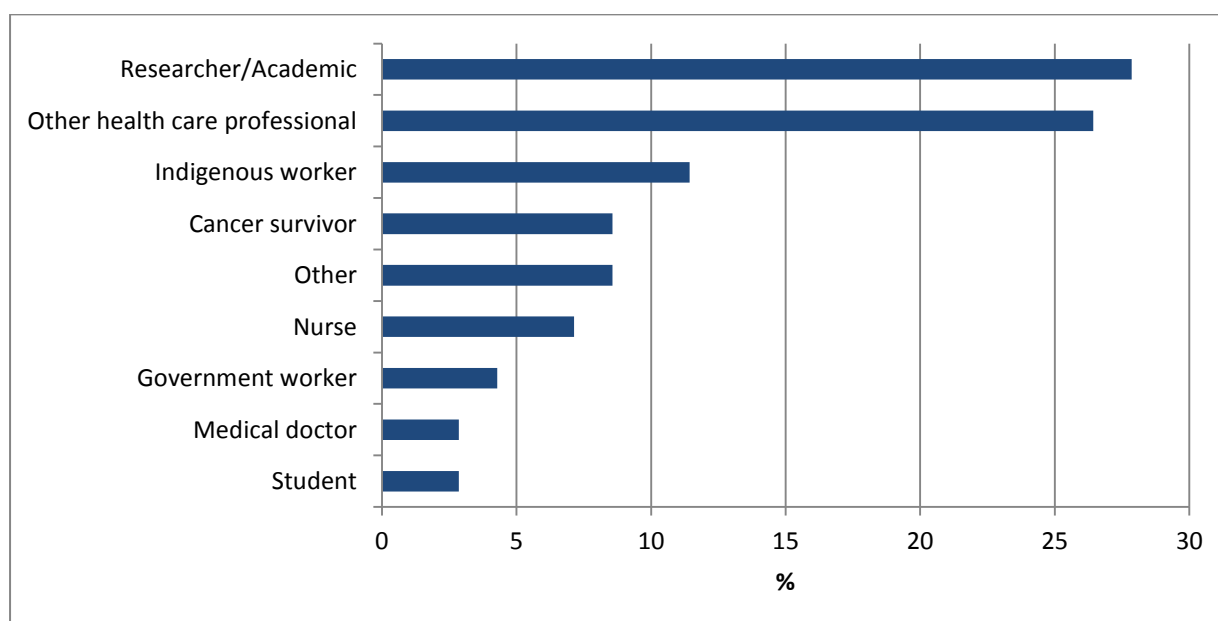




## 14. Post-conference Evaluation

We received a good response from delegates (44.7%) completing the post conference evaluation survey. Of the 140 survey respondents, most were registered as standard delegates attending the conference (47.1%), with the other respondents being concurrent session speakers (37.9%), plenary session speakers (5.7%), volunteer or conference support staff (5.7%), and trade exhibitors (3.6%).

The majority of respondents identified as researcher/academic and health care professionals (see graph below). The *Other* category in the graph below included Elders, Aboriginal artist, administration, media and staff.



The majority of respondents resided in Australia (77.9%), Canada (11.4%), New Zealand (7.1%), United States of America (2.1%), with one respondent from Myanmar and another from India (0.7%).

Mostly, respondents heard about the conference from a colleague (47.9%) or via email (27.1%).

The majority of feedback was positive and constructive with delegates selecting mostly *Excellent* or *Very Good* when asked about different components of the conference (see table below).

	% of respondents					
	Excellent or Very Good	Good	Fair	Poor	Not Applicable	Other
Registration Process	82.1	8.6	4.3	0.0	3.6	1.4
Registration Onsite	86.4	7.1	1.4	0.0	5.0	0.0
Conference Website	63.6	25.0	7.1	0.7	0.7	2.9
Delegate Satchel contents	46.4	34.3	7.1	1.4	7.1	3.6
Conference Venue	84.3	10.7	2.1	0.7	0.0	2.1
Plenary Sessions	82.2	12.1	2.1	0.0	1.4	2.1
Concurrent Sessions	77.1	17.9	2.9	0.0	2.1	0.0
Mini-Oral Sessions	47.1	22.9	1.4	0.7	23.6	4.3
Monday Workshop	15.7	0.0	0.7	0.0	82.1	1.4
Early Morning and/or Lunchtime Sessions	37.9	15.7	2.1	0.0	43.6	0.7
Yarning Circle	59.3	7.1	2.1	0.0	27.1	4.3
Declaration Space	29.3	24.3	9.3	0.0	35.0	2.1
WICC Overall	89.7	9.6	0.7	0.0	-	-

## Yarning Circle

Respondents indicated that they felt the Yarning Circle added an important element to the conference (76.4%) and that they felt welcomed into the Yarning Circle (60.7%).

Respondents commented that ‘the Yarning Circle was probably one of the most important aspects of the conference’ and that it was ‘a great way for people to just share information, I wish more researchers and doctors had sat in’.

While many respondents indicated that the Yarning Circle was an inclusive space, some were ‘unclear whether it was for Indigenous people only and whether it was appropriate for non-Indigenous people to join in’.



Canadian Elders present in the Yarning Circle

The Yarning Circle provided ‘an opportunity for our Indigenous people to share not only in solutions or common experiences but also share in support of our traditional methodology and modern solutions in cancer care for our people’.

In future conferences, more communication could be provided to delegates about the role of the Yarning Circle and that everyone is welcome to participate.

## Presentations



The majority of respondents (65.7%) indicated that the mix of research, clinical, health service and consumer presentations was appropriate. Some of the comments suggested that the same research and statistical information was repeated during the conference and that it would have been great to have more discussions with panels.

*“There was a wide range of great presentations but perhaps a little more focus on what is working in communities and for consumers would be better. I heard many people say too many stats and too academic, when what they really wanted was practical ideas.”*

Respondents clearly identified David R. Williams’ presentations, Archie Roach’s performance at the dinner and his conversation with his surgeon, Louis Irving, in Plenary 5 as key highlights of the program.

Respondents also enjoyed the varied program, mix of international delegates, opportunities to network and quality of the keynote speakers.

Comments suggested that the conference had a ‘positive’ atmosphere and that ‘it was wonderful to see representatives of Indigenous cultures share their perspectives on cancer control and the impact of the disease on communities, and to see the commonalities across cultures’.



Archie Roach and surgeon Prof Irving chat during Plenary 5

*“Very friendly group of presenters and attendees. Easy to go from session-to-session, even to hop between sessions to hear particular speakers.”*

The strong attendance by Indigenous people and their involvement in the conference was important to respondents as were the cultural performances during the social events and opening and closing plenary sessions.

*“I also really liked attendees’ genuine willingness to share experiences, and welcome a non-Indigenous worker. Thank you.”*

## *What we could do differently*

A number of respondents commented that there was too much information for the time allocated and that there wasn’t enough time to have questions at the end of sessions. For delegates who attended the early morning sessions, the days were very long and people would have preferred more time to digest and discuss the information between sessions.

It was suggested that the cost was prohibitive for people who wanted to self-fund their registration or not-for-profit organisations.



*"I found there was a significant amount of time spent presenting very dense data at quite a fast pace. It would have been wonderful to have a summary of the data made available for reading, and made the focus of the presentation around the findings, and plan for the future."*

### *Planning for the next conference*

Respondents commented that they would like to see more focus on 'putting conference learnings into action' and 'more of what is working in different communities'.

There were a few respondents that would like to see 'more around cultural awareness courses that are being run to educate non indigenous health care professionals' and 'practical steps for Indigenous and non-Indigenous people to work together respectfully'.

*"Perhaps some of the projects that presented that were in progress could present follow up information at future conferences."*

Overall, respondents enjoyed the WICC and are anticipating the next conference.

*"The organisation and planning obviously required a united team approach and this was evident in the quality of speakers and presentations as well as overall coordination. Thank you, it made my long flight and the expense worthwhile."*

When asked where the next conference should be held, respondents suggested Canada (37), New Zealand (32), United States (11), and Australia (10).





## 15. Outcomes

The World Indigenous Cancer Conference 2016 was the first of its kind and was a significant step in improving cancer outcomes for Indigenous peoples around the world. WICC 2016 celebrated Indigenous cultures and highlighted partnerships both internationally and with Indigenous communities.

The conference theme was *connecting, communicating, collaborating*; and each of these elements were achieved by:

- Connecting a large number of international and national delegates that included researchers, public health practitioners, clinicians, nurses, advocacy groups, allied health and other related professionals, and Indigenous community groups and leaders from around the globe. We were able to reach our target of over 300 registered delegates and we met our goal of ensuring that Indigenous cancer survivors and community members participated in both the Yarning Circle and conference program.
- Communicating about a wide range of issues that impact on cancer health outcomes for Indigenous people. Discussions centred on, not only the barriers to improving these health outcomes, but also about what is working now and how we can learn from that.
- Collaborations between research institutes, non-government organisations, health centres, and Indigenous organisations were evidenced throughout the conference. Discussions about research and programs conducted to date highlighted that this type of work with Indigenous people cannot be performed without partnerships. Collaborations are a necessity in order to create networks and conduct respectful research in partnership with Indigenous communities. This conference provided the opportunity for new relationships across the world.

A website is being established to continue *connecting, communicating, and collaborating*. This website will allow for continued conversations amongst WICC 2016 delegates, in addition to those people unable to attend. Through this website, people will be able to register their interest in joining a network of people around the globe that is focussed on improving health outcomes for Indigenous people. Details will be distributed in the near future.

For an inaugural conference the energy, enthusiasm for discussion, and willingness for delegates to participate in the full program, supported the value in holding an international conference of this type. The mix of consumer, academic and health services professionals represented is testament that future conferences need to occur to continue the discussion to improving outcomes for Indigenous communities globally.



