Marie McInerney reported on the inaugural World Indigenous Cancer Conference in Brisbane, from April 12-14, for the Croakey Conference News Service.

Croakey is a social journalism project for public health based in Australia.  
http://croakey.org
Marie McInerney writes:

Efforts to reduce the incidence of cancer in Indigenous communities across the globe were on the agenda of the first international conference of its type, held in Brisbane.

Hosted by the Menzies School of Health Research, in partnership with the International Agency for Research on Cancer (IARC), the theme of the inaugural World Indigenous Cancer Conference was ‘connecting, communicating, and collaborating’.

The experiences of consumers and how they can inform prevention and treatment strategies were also a major focus.

Among more than 300 delegates from around the world were Indigenous research leaders from Australia, New Zealand, the United States, Canada and beyond. Presentations ranged from the incidence and mortality of cancer among the Greenlandic Inuit through to oral cancer among the Mullu Kuruma, Paniya and Kattunaikka tribes of India.

The three-day conference program (April 12-14) looked across the entire cancer continuum, from cancer prevention through to end of life care for Indigenous communities across the world.

Its aim is to reduce Indigenous cancer disparities, by bringing together Indigenous communities and experts to discuss the latest findings in the field, to stimulate international collaborations and to encourage high quality cancer research.

A pre-conference workshop Racism and Health Workshop – Learnings for Cancer was hosted by keynote speaker Professor David R Williams, who is the co-leader of the Cancer Risk Reduction and Disparities Program at Harvard University, and Dr Naomi Priest from Australian National University.
It discussed the multiple ways in which racism influences health and health inequalities, with particular implications for Indigenous cancer research, policy and practice, and looked to evidence regarding promising interventions to reduce racism and its harmful health effects.

See background reading suggestions from Naomi Priest here:

- Is racism a fundamental cause of inequalities in health?
- Understanding associations between race, socioeconomic status and health: Patterns and prospects
- Racism as a determinant of health: A systematic review and meta-analysis
- Self-reported experiences of discrimination and health: Scientific advances, ongoing controversies, and emerging issues (paywall)

As well as performing at the conference dinner, legendary Indigenous singer-songwriter Archie Roach participated in the Wellness and Survivorship Plenary session, talking about ‘the patient and doctor conversation’. In recent years, he has suffered a stroke and had half of his lung removed, after he was diagnosed with the early stages of lung cancer.

A Yarning Circle also featured throughout the conference as a space for stories about cancer survival, cancer care and screening services, health and wellbeing programs, cancer research and education programs for Indigenous people internationally.

Menzies co-hosts the National Indigenous Cancer Network (NICaN), which works to translate Indigenous cancer research into practice so that what’s known about cancer is available for use by people with cancer, their families, practitioners, policy makers and researchers.

NICaN ambassadors and Aboriginal community-controlled health services were involved in developing the three-day Yarning Circle program.

A major focus of Menzies research is on improving Indigenous cancer patients’ experiences through their cancer journey and cancer outcomes. It says:

“Navigating one’s way through the health care system can be arduous and fraught with uncertainty and fear for any cancer patient.

This common problem can be exacerbated for an Indigenous person. Indigenous adult cancer patients report substantial unmet supportive care needs, including provision of transport and appropriate travel arrangements, suitable accommodation for both the patient and their support person and extra psychological support.”

Other keynote speakers and presenters included:

- Professor Tom Calma AO – Chancellor, University of Canberra and National Coordinator of Tackling Indigenous Smoking (Australia)
- Dr Linda Burhansstipanov – Director of Native American Cancer Research (US)
- Dr Chris Wild– Director of International Agency for Research on Cancer (France)
- Professor Helen Zorbas AO – CEO of Cancer Australia
- Associate Professor Gail Garvey –Principal Research Fellow at Menzies School of Health Research (Australia)
Garvey, who is #WICC2016 Committee Chair, said cancer has been largely overlooked among Indigenous populations globally, despite research showing they have significantly greater mortality and lower cancer survival rates.

Cancer is the second leading cause of death among Aboriginal and Torres Strait Islander people and is responsible for more deaths each year than diabetes and kidney disease.

Menzies reports that while the death rate for all cancers combined is significantly higher for Indigenous Australians than other Australians, Indigenous Australians have a lower incidence of cancers commonly diagnosed in the non-Indigenous population and a higher incidence of less common cancers. These include cervical, liver, uterus, lung and other smoking-related cancers. For example, the incidence rate of cervical cancer is almost three times higher for Indigenous Australians than for non-Indigenous Australians (18 and 7 per 100 000, respectively).

A number of key presentations at the conference looked at research behind those figures, particularly why, despite a similar overall incidence of cancers, Indigenous people have higher mortality rates than other Australians. Menzies says a number of factors may be behind the higher death rates, including later diagnosis, reduced uptake of or access to treatment, greater comorbidities, and higher rates of more aggressive cancers.

Ahead of the conference Garvey said:

- 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.

- WICC 2016 will provide opportunities to foster new collaboration, enhance capacity, and share knowledge and information about cancer and Indigenous people internationally.
Implicit bias: what is it, and why does it matter in healthcare? (Timely context for Gurrumul’s case)

Marie McInerney writes:

Concerns about the NT health system’s treatment of internationally acclaimed Indigenous musician Gurrumul Yunupingu were a hot topic at a timely workshop held in Brisbane, ahead of the opening of the inaugural World Indigenous Cancer Conference.

But those at the pre-conference workshop on racism and health were not only concerned about the musician’s clinical care.

They also highlighted hospital management’s immediate and defensive dismissal of the possibility of racial discrimination, when mounting evidence tells us it is not only likely in health systems, but probable and inevitable without major intervention.

Professor David R Williams, Professor of Public Health and of African and African American Studies and of Sociology at Harvard, said the hospital management’s comments were an illustration of “the core paradox” of health care, where mostly well-meaning and highly educated health professionals go to work intending to do their best – “and yet they produce a pattern of care that is clearly discriminatory.”

Williams was a keynote speaker at the opening plenary of the #WICC2016, which is hosted by the Menzies School of Health Research, in partnership with the International Agency for Research on Cancer (IARC).

Alongside his Australian research colleague Dr Naomi Priest, he hosted a four-hour intensive workshop on the multiple ways in which racism influences health and health inequalities and the influence of systemic, interpersonal and individual racism – both within and outside of the healthcare context.

They have numerous collaborations, including a recent invited commentary on understanding associations between race, socioeconomic status and health, as part of a special issue in Health Psychology, a US American Psychological Association journal.

The workshop inevitably led to discussion about Gurrumul’s case, which has been referred to the Northern Territory’s Health and Community Services Complaints Commission.
With many of the workshop participants having come from New Zealand and Canada and not knowing about the public row, Menzies’ Senior Principal Research Fellow Professor Joan Cunningham described the concerns that had been raised by Gurrumul’s management and doctor, Paul Lawton, as well as the NT Health Minister’s allegations of a “publicity stunt”.

“The point I think that was really being raised is: if this is what happens to someone of such high profile, what’s it going to be like for the next person?” Cunningham said.

“Paul Lawton is not talking about individuals acting in a racist manner, he’s wanting to talk about the system and how it works, or more importantly how it doesn’t work for everybody,” she said.

“So the defence (from the hospital) that ‘these people aren’t racists, they’re working very hard’, completely misses the point.”

Implicit bias matters

To understand unconscious discrimination or implicit bias as it’s also known, Williams told the workshop about a collection of works known as the Bound Encoding of the Aggregate Language Environment (BEAGLE), which contain 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 terrible levels of stereotyping, particularly of black Americans.

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 (see slides at the bottom of this article for more details).
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.

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,” Williams said.

He said people who say they would “never” discriminate are often just unaware of it because “they had no intent to do it”. Inevitably that also included health professionals, he said, citing evidence of **differences in treatment for minority groups** across “virtually every intervention” – from the most simple to the most complex.

As an example, Williams said one study looked at whether race made a difference as to whether pain medication would be administered when patients arrived at a US hospital emergency department with a broken bone.

Adjusted for gender, health insurance status, English spoken, time spent in Emergency, how severe the fracture was, the single biggest predictor was whether the patient was Hispanic. Hispanic patients were 7.5 times more likely to not get pain medication. The same applied for black Americans when the study was repeated elsewhere.

And, Priest said, Indigenous Australians experienced the same inequality in treatment.

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**Discrimination and Indigenous Healthcare**

- Five studies have shown disparities in medical care experienced by Indigenous patients in Australia
- Indigenous patients with the same characteristics as non-Indigenous patients were about a third less likely to receive appropriate medical care across all conditions (Cunningham 2002) as well as for lung cancer (Hall *et al.* 2004) and coronary procedures (Coory & Walsh 2005) in particular
- Indigenous patients were only one-third as likely to receive kidney transplants (Cass *et al.* 2003)
So can anything be done?

Yes, Williams said – but he warned it takes time and “a steady drumbeat” of increasing awareness about the role and impact of implicit bias.

He recommended two US studies:

- **Reducing Racial Bias Among Health Care Providers: Lessons from Social-Cognitive Psychology** recommending a set of evidence-based strategies and skills, “which can be taught to medical trainees and practicing physicians, to prevent unconscious racial attitudes and stereotypes from negatively influencing the course and outcomes of clinical encounters.”

- **Long-term reduction in implicit race bias: A prejudice habit-breaking intervention**, which reported a long-term reduction in implicit race bias through ‘prejudice habit-breaking intervention’.

**Systemic and structural interventions needed**

But Williams said implicit bias is just one “slice” of discrimination, which is also systemic and structural.

He pointed to a systems change intervention in the United Kingdom, where the National Health Service has introduced a mandatory workforce race equality standard that requires NHS organisations to collect baseline information on nine indicators of workforce equality for ethnic minority staff. Organisations that fail to make progress are to be held in breach.

“We need more systems level changes that don’t rely on the good intentions of individuals,” he said. (See also this paper, *Promoting equality for ethnic minority NHS staff – what works?*)

In discussion about solutions at the workshop, Associate Professor Gail Garvey from Menzies Research said there had been good moves in Australia to make medical and nursing school curricula more “culturally competent”.

However, once graduates got out into the system, they were being told by senior clinicians to forget them, that “this is the way we do things”. It was going to take many years for the current training to have a real impact in the system, she said.

Similar problems were seen in prevention and screening programs where Aboriginal and Torres Strait Islander people were left out of the process. “Systems have to recognise they’re actually discriminating against our people.”

Another delegate asked whether it was possible to get “traction” by putting the focus around patient-centred care: “every patient is different so you can’t treat them all alike”.

A New Zealand delegate said one of her country’s two medical schools had reached a major milestone, and now had the same proportion of Maori students as the general population, with the other one getting close. It represented “substantial progress”, she said, with the medical colleges now trying to make similar inroads with specialists.

Williams asked what was being done, in a systematic way, in Australia to increase the pipeline of Indigenous people into the health care workforce.

An Aboriginal health worker said potential medical students were being nurtured from high school, but she also wanted to see due recognition for her profession.
“A lot (of health professionals) don’t recognise us as anything other than ‘their assistant’, when truly these positions hold a knowledge base that all of the other professions can’t and don’t hold,” she said.

• On Twitter, follow @D_R_Williams1 and @naomi_priest
You can track Croakey’s coverage of the conference here.

Implicit bias: what is it, and why does it matter in healthcare? (Timely context for Gurrumul’s case)

From the Twittersphere

Marie McInerney @mariemcinerney · 7h
Typical clinical encounter (time pressure, snap judgements) embeds conditions that maximise implicit bias @D_R_Williams1 #WICC2016 #Gurrumul

Marie McInerney @mariemcinerney · 7h
‘These people aren’t racists, they work hard’ - missing point about systems, unconscious bias #Gurrumul #WICC2016

abbey diaz @AbbyDiaz_says · 6h
This was a great point raised today with some examples from NZ and US showing this can work. #WICC2016

Marie McInerney @mariemcinerney
To stop racial bias in health care, need more system changes that don’t rely on good intentions of indivs @D_R_Williams1 #WICC2016

Further reading and viewing

• Previously at Croakey – What do health leaders say about Gurrumul’s care and wider concerns?

• Dancing with power: Aboriginal health, cultural safety and medical education – thesis by Gregory Phillips.

• Test your implicit bias here.
Watch previous presentations by Professor Williams on the YouTube clips below:

Dr. David R. Williams: The Social Factors of Health

Dr. David R. Williams: “Racism and Health: Findings, Questions...”
National Cervical Screening Program faces critical test: can it improve screening rates of Indigenous women?

Marie McInerney writes:

How will the new cervical cancer screening program, to be rolled out across Australia from May 2017, address historic failures to engage with Indigenous women?

It’s a big question following the release of a landmark study showing 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).

The signs are not promising. Formal consultations are due to begin with Indigenous health services in June – less than a year before the new national screening regime begins, and five years since the changes to the program were first mooted.

The Menzies School of Health Research released the research findings at the World Indigenous Cancer Conference in Brisbane, saying 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.
Landmark research

To fill that gap, the Menzies project, led by researcher Lisa Whop, conducted 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.

The study 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.

A parallel study by 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.

The study in Cancer 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. 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.

“Cervical cancer is a devastating disease for Indigenous women, their families and communities, made more so by how preventable it is,” she said.

For Whop, the big lesson of the study was: “you can’t improve what you can’t see”, but she said the true success of the research was “what happens next”.

The renewed NCSP, which from 1 May 2017 will replace Pap testing every 2 years with a test for HPV every 5 years, is an important opportunity for the program to engage more effectively with Indigenous women, she said.

So it was timely on Wednesday to have key figures involved in the new NCSP hosting an early morning symposium at the conference on the changes, asking “what are the key issues for Indigenous women in the transition of the program to the primary HPV screening?”

Karen Canfell, Director of the Cancer Research Division at Cancer Council NSW, said many non-Indigenous women also did not have Pap tests, but that there were also specific issues facing Indigenous women.

These included: fear of cancer and the belief that it is a terminal illness; fatalism and the belief that nothing can be done; stigma around sexual activity, fear to leave family to travel for healthcare, personal and community stories about negative experiences with the health system, and the costs and travel involved in accessing health services.
Describing Whop’s work as “seminal”, Ian Hammond, chair of the Steering Committee for the Renewal Implementation Program, assured delegates that legislation was being progressed to allow pathology forms to record Indigenous status and send the data to the national register.

“This is all happening as we speak,” he said.

**Concerns about consultation processes**

But there was no news of a formal engagement strategy with Indigenous services or communities to drive the new NCSP, nor even whether there has been discussion over whether the chosen way of inviting Australian women to participate in the new screening tests – a letter sent on their 25th birthday – will work any better for Indigenous women than routine letters have in the past.

In fact, some delegates were surprised to find they were the starting point for consultations.

Hammond and Canfell conducted a “brainstorming” session at the symposium, saying the “output of today’s discussion will very much directly inform the development of materials and health promotion strategies for Indigenous Australians.” The Commonwealth was “very keen to get this right”, they said.

However, one table expressed concerns with the process, saying they had no Aboriginal and Torres Strait Islander women at their table and felt “uncomfortable making suggestions on their behalf”. They wanted to be reassured there would be direct consultations with the Indigenous community.

Yes, they were told, “this is the very beginning of the process”, and the Steering Committee would be working with Menzies to set up a consultation roundtable for Indigenous groups in June.

“That will be the next step (and) part of that discussion will be what further consultations are needed,” Canfell said.

Speaking later to Croakey, Hammond said it was “not reasonable” to say the NCSP had failed Indigenous women, who he said were recognised broadly as a “hard to get at” population.

He also rejected the suggestion that the Steering Committee was starting Indigenous consultation too late. “You have to get everything into place before you can communicate the messages,” he said. “There’s no good, for example, going out there and saying we’ll offer you ‘self-testing’ if self-testing is not approved (yet).”

At least there is agreement that some Indigenous primary care services have shown the way, achieving better screening participation than the national rate.

“It can be done,” said Associate Professor Gail Garvey, the leader of Menzies’ Indigenous cancer research group.

“The national program needs to understand and build upon what these services are doing so successfully. The need to engage with Indigenous women and Indigenous communities will be critical to the success of the Renewal for Indigenous women.”
You can track Croakey's coverage of the conference here.

National Cervical Screening Program faces critical test: can it improve screening rates of Indigenous women?

#WICC2016

Graphic provided by the Menzies School of Health Research

Watch this interview with Dr Lisa Whop

Lisa Whop talks about new research #WICC2016

Cancer Australia @CancerAustralia · 1h

Congratulations to @Lisa_J_Whop emerging new research WICC work on Indigenous cervical screening data #WICC2016

Croakey “Conference News Service”
Community helps cancer patients navigate complex health system

Marie McInerney writes:

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, 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 find 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.

Family violence advocates have similarly looked through the recent Royal Commission into Family Violence process in Victoria for the appointment of women’s advocates, to ‘walk alongside’ women through complex legal processes.

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. The Native Sister led her into the building by a back way.

For others, it’s about being 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.

It can also be simply the use of language. Burhansstipanov says:

- “For some of our people, to be told your cancer test is ‘positive’ means it’s positive news, that is, you don’t have it.
- The navigator is there to ask questions on the patient’s behalf and to make sure the clinician is getting across the right information.
- The end run for us is to see people get earlier and earlier diagnosis.
- At the beginning we were primarily getting people in stage 3 and 4 of cancer, now the majority are zero, one, and two. It’s because of the navigators.”
You can track Croakey’s coverage of the conference here.

You can watch this video interview with Dr Linda Burhansstipanov.
Gaps in palliative care and support

Also speaking in the session, Professor Patsy Yates, President of Palliative Care Australia, said Burhansstipano’s work underscores how important it is to have an Indigenous health workforce in palliative care.

Yates said the data was not strong, but there were strong signs that Indigenous people have very different access to palliative care services. BEACH survey data showed that of nearly 98,000 GP encounters, there were no referrals of Indigenous people to palliative care.

Reconciling that data suggested that Indigenous people either went into palliative care late or not at all, and that they received more end of life care in acute health settings. “If they are having to end up in Emergency Departments then we have big issues to address,” she said.

The conference also heard latest progress on a number of investigations by the Menzies School of Health Research into unmet needs and quality of life issues for Indigenous cancer patients.

Dr Christina Bernardes said preliminary findings of a national assessment of supportive care needs of Indigenous patients showed psychosocial and practical assistance were particularly important, ahead of hospital or information concerns.

The most commonly reported moderate-to-high unmet needs were ‘worrying about your illness spreading or getting worse’, ‘anxiety’ and ‘money worries’, including ‘finding a place to stay’ when having to travel, often far from home, for treatment.

Money worries, including for those who were not having to travel far, were also the main concern for patients in a cross-sectional study by Abbey Diaz, which investigated the association between comorbidity and supportive care needs among newly diagnosed Indigenous cancer patients in Queensland.

Given the concerns, she suggested there was an opportunity for tele-oncology, which could reduce costs on patients and the system, reduce social isolation and improve patient doctor communications, for those who lived too far or were too unwell to get to clinics.

Detailing further research into health-related quality of life among Indigenous Australians diagnosed with cancer, Associate Professor Gail Garvey of the Menzies said clinicians have increasingly recognised that while morbidity and mortality are important, more attention needs to be paid to the quality of life in a patient’s care, given the very significant impact on peoples’ lives, families, and work.

As part of a larger, longitudinal study, the research surveyed Indigenous cancer patients at four clinics in Queensland who were receiving treatment or were about to, and who were well enough to participate.

While small, the study found that aspects of culture, values and spirituality are key to Indigenous peoples’ quality of life. Patients who spoke an Indigenous language at home, who maintained contact with other Indigenous people, and who lived outside of major cities were likely to report higher health related quality of life than comparison groups.
You can track Croakey's coverage of the conference here.

Community helps cancer patients navigate complex health system

#WICC2016

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Sue Moore @SueMoore09 · Apr 12
Cancer patients with strong cultural supports report higher quality of life @garvey_gail @AbbayDiaz_says @wicc2016

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Sue Moore @SueMoore09 · Apr 12
Important to have culturally appropriate tools to measure supportive care needs for Indigenous cancer patients @AbbayDiaz_says @wicc2016
A collaborative Twitter-essay from the World Indigenous Cancer Conference (plus Selfies)

Below is a Twitter essay that conveys a strong sense of the participants in the inaugural World Indigenous Cancer Conference.

Kerry Arabena @ArabenaKerry - 2m
Great way to open #WICC2016! Congrats Gill Garvey Conf Chair and all involved. @croakeyblog @oneindia
You can track Croakey’s coverage of the conference [here](#).

A collaborative Twitter-essay from the World Indigenous Cancer Conference (plus selfies)

#WICC2016

Croakey

“Conference News Service”
You can track Croakey's coverage of the conference here.

A collaborative Twitter-essay from the World Indigenous Cancer Conference (plus Selfies)

#WICC2016
You can track Croakey's coverage of the conference here.

A collaborative Twitter-essay from the World Indigenous Cancer Conference (plus Selfies)

#WICC2016

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**abbey díaz** @ AbbeyDiaz_says - 11h
I have no words for this most beautiful exchange, so photos only will have to suffice #WICC2016 @garvey_gail

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**Marie McInerney** @ mariemcinerney - 56m
William Barton & his mum Aunty Delmae Barton close inaugural #WICC2016 with ‘My Island Home’ - our unofficial anthem

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Croakey

"Conference News Service"
You can track Croakey’s coverage of the conference here.

All the Selfies

As you will see, when Professor Kerry Arabena sent out a #20SelfiesorBust challenge, the flurry of action sent Twitter into a meltdown (almost a true story – Twitter did collapse on that day).

A collaborative Twitter-essay from the World Indigenous Cancer Conference (plus Selfies)

#WICC2016
You can track Croakey’s coverage of the conference here.

A collaborative Twitter-essay from the World Indigenous Cancer Conference (plus Selfies)

#WICC2016
A collaborative Twitter-essay from the World Indigenous Cancer Conference (plus Selfies) #WICC2016

Croakey
“Conference News Service”

You can track Croakey’s coverage of the conference here.
You can track Croakey’s coverage of the conference here.

As far as the Twitter competition went, shall we call this one “winner”?

![Image of two women smiling and wearing sunglasses]

Kerry Arabena @ArabenaKerry · 22m
#WICC2016 @croakeyblog best selfie #20Selfiesorbust. Me & mum, 71, cancer survivor, cool aviator glasses wearer. ❤️
Archie Roach – and a truly amazing conversation with his doctor

Marie McInerney writes:

One of the highlights of the inaugural World Indigenous Cancer Conference in Brisbane was to sit in on an intimate discussion between legendary singer Archie Roach and his doctor Associate Professor Lou 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 longtime 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.
‘It’s my healing’

The conversation had begun the night before when Archie performed at the conference gala dinner in front of Elders and delegates from Indigenous communities across the globe, representing Aboriginal and Torres Strait Islanders, Native Americans, Canadian First Nation, Inuit and Metis people, and a larger Maori contingent from New Zealand.

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. Everytime I sing it, it lets a little bit go.”

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This story’s right, this story’s true
I would not tell lies to you
Like the promises they did not keep
And how they fenced us in like sheep.
Said to us come take our hand
Sent us off to mission land.
Taught us to read, to write and pray
Then they took the children away,
Took the children away,
The children away,
Snatched from their mother’s breast
Said this is for the best
Took them away.
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As one delegate said: “He put the whole conference into song”. 
In conversation
The following day Archie and Lou Irving spoke on the conference’s main stage, in a session on ‘the patient and doctor conversation’. It sounded like they had had many such talks before.

As Irving led Archie in conversation, he asked how Archie had felt about seeking medical attention, what prejudice he had experienced in the health care system, the role of family and what techniques he uses to maintain meaning in life.

Irving admitted he didn’t know who Archie Roach was when they first met in a hospital consulting room in 2011. He only found out about him when he told friends he had met “this interesting Indigenous man”.

At that first meeting Archie was surrounded by doctors. Multidisciplinary care can deliver the best outcomes in health but Irving was “struck by the parallel worlds” that were present in that meeting. Archie is the only patient with cancer Irving has had who has not asked him, “how long have I got?” “You seem to live in the present, not future,” Irving told Archie.

“It took me a couple of weeks to realise there was more to Archie than the spot in his lung. We learn from our patients,” Irving said. “I’ve learnt an enormous amount.”

Barriers to seeking health care
Irving began by asking what was the biggest barrier Archie faced in seeking medical care when he realised there was something wrong.

This was an issue that arose in many contexts and forums at the conference, with Indigenous people suffering from late diagnosis and treatment.

“The biggest barrier I think is that I’m an Aboriginal man….we’re just too tough for our own good,” Archie said, recalling the scene in Monty Python’s The Holy Grail where a knight fights blindly on – “it’s just a scratch!” – despite losing his arms and his legs.

| “We suffer in silence and we don’t want to talk about what we’re going through.” |

He had noticed that things weren’t quite right; he had troubles with breathing and walking.

| “Still I chose to ignore it, (thought) it’ll be right, give it a couple of days, it’ll come good.” |
Archie also shared with many other Indigenous people a mistrust of doctors, because of the experience of Aboriginal and Torres Strait Islander people in the past.

“I now realise there are good people out there, good doctors, who have worked with Aboriginal people and understand the problems we have with dealing with society in general,” he said.

Irving, who he now counted as “a good friend”, was one of those, he said.

**The cancer journey: a tough road**

First, as Archie detailed in [this story](#) in *The Saturday Paper*, he had a stroke: he was in the Kimberley doing workshops for children, when he got up one morning, fell over and couldn’t move.

While he was recovering, his manager, Jill Shelton, got a feeling that something else was wrong.

*The Saturday Paper* quotes Shelton saying, “I don’t know what it was really. Being a smoker, and Archie was a heavy smoker, his breathing was always a bit dodgy. And it wasn’t [because of] coughing, it was just a feeling that something else might have been happening.”

Archie told the conference Shelton had played a big part in his survival, pushing “behind his back” for him to get treatment, insisting he undergo an x-ray, asking the hard questions that he tended not to.

Still, for a time, it was all too much. He didn’t think he had the strength for another big fight.

“I was listening to all this medical talk about the lungs, whether there would be radiotherapy, an operation etc, and I actually thought to myself, ‘maybe we’ll just leave it, just let it go’.

“I don’t know why. I’d come to a stage in my life where I thought: I went through a lot of trouble, heartache, pain. I was taken away as a kid, (went through) jails, institutions, alcoholism, homelessness.

“But I came good. I got through that, I dealt with it, got my life together and straightened out….I’m grateful for those years that I had, and I thought, ‘Maybe it’s time to go’.”

What kept him going was wanting to still be there for his children and grandchildren, and the news that he would still be able to sing after the operation.

But Archie admitted it’s been a tough road, with the removal of part of his lung leaving him with a significant disability.

You wouldn’t have known it when he sang. The raw power of his voice remains strong – singing uses muscles differently, he later explained.

But the diminished lung capacity exhausts him. It often keeps him limited to just a few songs, unable to walk even small distances, and at times strapped to an oxygen tank.

**Has it been worth it, Irving asked?**

Archie replied: “At first, I didn’t think so because I still have problems …I deal with it, I manage it as best I can. It’s far better than not being here that’s for sure…

“I actually love life now and any hesitation I had for the operation, for getting well, going through with the operation…it’s all gone.”
Exercise has helped. And Irving has taught him to take some time for himself, to take some ‘me time’.

"You hear about it, but it’s more than just a cliché, it’s actually true. You have to find time for yourself, give yourself some space, that’s important."

Archie goes back when he can to Killarney, in rural Victoria, near the Framlingham mission, to sit outside, be part of nature.

"There’s this one beautiful bird, a blue wren. I see it all the time, a most beautiful bird... Things like that: nature, country, that keeps me (going)."

And, of course, music too: “Music’s always been an important part of my continual healing.”

**Prejudice in health care**

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: have you found that in hospitals now or in the past?”

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.”

Sadly there are very recent concerns that even a high profile doesn’t assure proper treatment for Aboriginal people, with a complaint now lodged about the recent experience of Gurrumul Yunupingu, another renowned Indigenous musician, at the Royal Darwin Hospital.

As previously covered at Croakey, this case was much-discussed at the conference in the context of evidence about the role of institutional racism and implicit bias in the poorer treatment that Indigenous peoples experience in health care, around the world.

Speakers also highlighted these issues as a big factor in the reluctance of many to seek health care, a important point overlooked when mainstream health despairs of disengagement by “hard to reach” groups.

Archie said prejudice in health settings stops Indigenous people from seeking care. “Because if you make mistakes like that (confusing people because of their colour), if things like that occur in hospital, or we sense any sort of racism....we say ‘don’t worry about it’ and walk out. We pick up on those things.”

Irving invited the audience to contribute their thoughts about cultural and other factors that create barriers for health care workers in understanding Indigenous people or that leave Indigenous people feeling disempowered in the health care system, under pressure to “do what the system wants you to do.”
One delegate told of his work with Indigenous cancer survivors and how warm encounters with some medical teams had made a difference for them. It stood out from other medical processes, particularly where many specialists “divorce themselves” from the patient.

“For someone that’s going through the shock of being diagnosed, being away from family, in a foreign environment...people have said to me, just a little humanity, making conversation, will make a hell of a difference,” the delegate said.

A Royal Darwin Hospital health worker in the audience said the conversation highlighted the importance of having more Aboriginal Liaison Officers and Aboriginal health workers in the system, to play the “good advocate” role that Archie’s manager had seemed to play for him.

“Lots of patients in Darwin have English as their fourth language, they’re very shy, they’ve never been there before.” Often they can’t rely on family, as their relatives may feel “just as disempowered”.

She said: “We need a concerted effort to have Indigenous health workers in tertiary settings and interpreters in hospitals all the time, 24 hours in Emergency Departments, so when people come in, in distress, they can actually talk to someone about what’s going on.”

Asked by a Canadian First Nations delegate what was being done to teach culturally appropriate health practice in Australia, Irving responded that cultural awareness is now on the curriculum in every medical school: “but it is often dealt with in a very rational way.”

“The stories that Archie tells, highly emotionally intelligent stories...I think that’s a much better way to learn cultural awareness,” he said.

**Gold and platinum rules in health care**

Irving said he had been talking the previous night at the conference dinner about the pressures on health care workers that means they get to spend so little time with patients. It had reminded him of the concept of the ‘golden’ and ‘platinum’ rules.

“The ‘golden rule’ is what we all grew up with as health care workers: to treat people like we would like to be treated ourselves. The ‘platinum rule’ is to treat them how they would like to be treated.”

He said: “In order to practise the platinum rule, you need time to actually get to know a person, understand what their belief systems are, what their value systems are, and you need to do that before bad things happen because when bad things happen, it’s very hard to start from the beginning, to get to know the person (then).

“I mention this because I’ve spent time talking to Archie. It’s certainly enhanced my understanding.”

Irving talked about his own wake up call when Archie wasn’t recovering as well as doctors had hoped in the early post-operation days.

“His kidney function was not working quite as well as we had expected, we couldn’t understand it.”

“We only then found out that Archie only has one kidney, because he’d given the other one away.”
Irving said it was a mark of the nature of his patient, who is “actually the most generous person I’ve met”.

Archie downplayed his decision to donate: “It wasn’t a hard decision, it wasn’t brave, it was my brother. He was on dialysis and he needed a kidney. It’s a no brainer, you don’t think twice.”

But Irving said it also contained important lessons for health care professionals.

Normally, he said, someone who donates an organ is “very carefully followed” by the health system. Archie had not been.

“I should have been more careful and checked,” Irving said. “It could have had consequences.”

Maintaining hope

Looking at the slide (above) that formed the backdrop to the discussion, Joe Tooma from the Australian Cervical Cancer Foundation pointed out how important the last words, ‘maintaining hope’, are in the whole cancer journey.

He asked Archie: what helps you to maintain hope, what have you seen that works for others?

Archie said he gets a lot of hope through his music, particularly when he goes out to schools and later gets letters from little kids “about how they feel about things that have happened to us as First Peoples”.

“A lot of little ones, they get it, they understand. It’s things like that.

“Living each day, each moment, is important for me. That’s the hope I have, that I don’t lose sight of that. My hope for a better place for my grandchildren to grow up in and working towards that in whatever capacity I can, that’s how I maintain hope.
“Life is beautiful, I love life. It hasn’t been an easy journey coming through cancer, recovering from the operation, recovering mentally, physically, spiritually, which were all conflicting with each other. 

“But if I had to do it all again I certainly would, that’s for sure.”

Final snippets from Archie in conversation

On living in the present: “I don’t like to project too much. Each moment is important. If you don’t take the time to notice, see things in the moment, you’ll miss it.”

On diet: “Diet is such a hard thing. I don’t even like the word. It should be just ‘eat a bit better than you usually do’.”

On Indigenous values and remedies: “I’m always grateful for what I’ve been taught by my old people, my Elders, about how to walk in this world.”
Watch some interviews and stories from the World Indigenous Cancer Conference

As well as reading Croakey’s coverage of the World Indigenous Cancer Conference, you can watch several interviews via the Periscope app with keynote speakers and other presenters and participants at the inaugural event in Brisbane last week.

They are all available at Croakey TV – or watch them below.

You can also listen to more #WICC2016 stories here from @Indigistream – check them out: http://indigistream.com.au/

Lisa Whop talks about new research #WICC2016
Menzies School of Health Research researcher Lisa Whop talks about her landmark study which mapped, for the first time, low rates of screening of Indigenous women for cervical cancer and showed they had not improved at all over the 25 years of the National Cervical Screening Program (NCSP) which has delivered significant health benefits to non-Indigenous women.

Whop won a key research award at the conference for her study. As this Croakey story details, her findings raise big questions around how the new cervical cancer screening program, to be rolled out across Australia from May 2017, will address historic failures to engage with Indigenous women?

Professor David R Williams talks about racism and health at #WICC2016

Before the conference proper, Harvard Public School Professor David Williams delivered a four hour intensive workshop on the impact of race and racism on Indigenous health. Providing important context for discussions about the recent experience of Indigenous Australian musician Gurrumul Yunupingu, he talks here too about the role of both implicit bias and institutional racism in ongoing inequities in prevention, diagnosis, treatment and prognosis in cancer and other serious illnesses. His opening plenary address talked about the intergenerational health impacts, “biological weathering”, and the constant adversity faced in everyday life by minority groups, including Indigenous peoples.

Talking cancer care for American Indians with Dr Linda Burhansstipanov at #WICC2016
Native American Cancer Research director Dr Linda Burhansstipanov talks about the Native Sisters program which navigates a complex health system for Native American communities in cancer care.

**Susan Forrester from VACCHO talks Yarning Circles #WICC2016**

The Yarning Circle was a big hit at the conference, providing a space for Indigenous peoples from around the world to tell their stories, as health workers, researchers, and survivors of cancer.

Susan Forrester from the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) talks here about the history of Yarning Circles at recent conferences and why they work so well.

**Professor Tom Calma AO talking tobacco control at #WICC2016**

Another keynote speaker, Professor Tom Calma talks here 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.
BreastScreenWA’s mobile screening unit travels through remote Western Australian and has been boosting screening rates in remote Indigenous communities. Leanne Pilkington talks about the issues and challenges involved, and what works.

Artist Andrew ‘kurina’ Gall at #WICC2016

In this interview, visual artist Andrew ‘kurina’ Gall talks about his work, ‘Research: a never ending story’, commissioned by conference host, the Menzies School of Health Research.

Art and music were a big focus at the conference, both in research presented about the role of both in therapy (particularly for cancer survivors – including for legendary Indigenous Australian singer songwriter Archie Roach) and also as a celebration. Delegates got to see the Aboriginal dance group Nunukul Yuggera and the Malu Kiai Mura Buai dancers from the Torres Strait, as well as Archie Roach, performer, composer and didgeridoo star William Barton and his mum, “Dreamtime Opera Diva”, Aunty Delmae Barton.

The feature image on this post is from one of the postcards made by delegates at the conference.
Profiling diversity and innovation in Indigenous smoking programs

Marie McInerney writes:

Around the world, diverse and innovative programs are tackling high smoking rates among Indigenous communities, according to presentations at the World Indigenous Cancer Conference in Brisbane last week.

Some of these are big and nationwide like the Tackling Indigenous Smoking program led by Professor Tom Calma in Australia.

Others are small, innovative and targeted, from efforts to “Keep it Sacred” among the Navajo tribes in the United States, through to a board game developed to help Maori Aunties to discourage smoking among young pregnant women.

The conference also heard of the profound impacts of tobacco upon Indigenous communities.
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 also found that smoking is more common in Indigenous communities in all four countries than in their non-Indigenous counterparts.

Another key message from the conference was the impact of “stop start” government policies and a failure to address the social determinants of health that lead to high smoking rates in Indigenous communities.

Harvard Public Health Professor David Williams, who presented a keynote address on the role of race and racism in health, said one important way to address tobacco-related cancers in Indigenous communities is to “address stressors in smokers that drive them to smoke”.

It was also important to focus on the equity impact of anti-smoking policies, he said, where tobacco taxes have a bigger effect on poorer people.

One media campaign that he said had worked better with minority young people in the United States focused on the deceptive practices of the tobacco industry rather than on the health impacts of smoking.

Tackling Indigenous Smoking

Professor Tom Calma, Chancellor of the University of Canberra and a founder of the Close the Gap Campaign, is ever optimistic about the success of the Tackling Indigenous Smoking initiative, after the Federal Government last year committed funding and resources to a redesigned program.

He told that conference that the initiative, launched in 2010, has helped to reduce Indigenous smoking rates, that have been falling at a faster rate than was seen in the general population, and he expects the 2016 national census to confirm anecdotal expectations of more success.

Part of its power, he said, is to not focus on the perils of smoking – “that’s known” – but to talk about the benefits of non-smoking – “not blaming, but empowering”.

It’s targeted big sporting activities, like the popular Murri Rugby League carnival, which is smoke and drink free and requires all players to complete a ‘Health Check’ in order to participate, the Nuff of the Puff program aimed at young people, and the successful Break the Chain promotion which is also being used in mainstream campaigns.
But, he said, it had suffered from the “wax and wane” approach of governments – notably from a $30 million a year cut in funding under the Abbott Government and disruption of its work while a review of its operations was carried out by Assistant Health Minister Fiona Nash (see more detail in this previous Croakey story).

That had created workforce instability in the Tackling Smoking and Healthy Lifestyle Teams across the country, and disrupted goodwill that had been built up in communities and organisations since 2010.

As a result, he said, Australia is not going to meet its target of halving 2008 Indigenous smoking results by 2008.

“We have to rebuild all that now,” he said.

“If we have consistent government policies instead of the ‘stop start’ (approach) we’ve seen, the vulnerability of funding, and the demoralising of the community…. then we will see even faster gains,” he told Croakey.

“There’s hope that the new national Aboriginal and Torres Strait Islander Cancer Framework developed by Cancer Australia in partnership with Menzies School of Health Research will help to bring consistency and broader population based approaches.

Calma said it’s an easy-to-read document that is the result of extensive consultation with the Indigenous community, and “that everybody needs to sign up to”.

**Keep it Sacred**

Tobacco has been used by the Navajo, along with most other American Indian nations, for centuries as a medicine with cultural and spiritual importance, said Scott Leischow from the Mayo Clinic in the US.

Traditionally the Navajo healers would go into the mountains and collect what they call ‘mountain smoke’ that grew naturally, to use in their ceremonies. But over the decades, he said, it’s become more common to just go to the local store and buy commercial tobacco instead, helping to further normalise the use of tobacco and continue to grow high rates of smoking.

Leischow told Croakey the Mayo Clinic has been working to support tribal organisations that are supportive of the “Keep it Sacred” movement to reduce use of commercial tobacco, which should lead to reduced commercial tobacco-related illnesses and cancer disparities among American Indian and Alaska Native populations.
“So some of the tribal organisations are now working to create a policy within healing communities to only use mountain smoke,” he told Croakey. The Mayo Clinic has helped by making videos where healers talk about the role of commercial tobacco and how it has impacted on traditional ways, which will then be disseminated to schools and communities.

Leischow is also working with tribal organisations that are trying to promote smokefree workplaces and public places. This is a complex and contentious policy area, he said, with many American Indian communities fearful that smoking bans in casinos, which have become an economic lifeline for many, will impact on business.

(Check here to see success stories from Keep it Sacred).

Tradition and innovations

Conference keynote speaker Dr Linda Burhansstipanov, director of the Native American Cancer Research Corporation director, talked about another pilot intervention among around 250 Native Americans living in the Rosebud and Pine Ridge Indian reservations and Rapid City in South Dakota.

One-quarter were cancer survivors, she said, in an area where the majority of people with tobacco-related cancer were back smoking within two years of ceasing treatment.

The project used a combination of motivational support and nicotine replacement therapy (NRT).

A big feature was that participants were given a mobile phone, so they could receive tailored text messages each day: a traditional Indian quote and/or personal messages such as: “I am quitting smoking so I can watch my granddaughter go through ceremony”.

The cultural and ceremonial use of tobacco was an issue too with the community, although the novelty of the phones was a big one, with many participants having never had one before. In fact, Burhansstipanov said, some non-smokers had gone to the local casino, where smoking is permitted, to try to build up the carbon monoxide levels in their blood so they could qualify for the program. Others built up pretty high phone bills, just calling information lines.

But, she said, “that’s why they call it research” and while results are still unofficial it is showing great promise. Burhansstipanov said the norm for stop smoking interventions was to get a quit attempt rate of about 7 per cent, and up to 12 per cent in very effective interventions.

As of October 2015, she said, 45 per cent of study participants had attempted to quit. They expect a lot of relapses, but also attempts to try again. “The number of times people restart makes it more likely they will quit in future.”

Game time

Burhansstipanov was speaking at an early morning symposium on traditional and innovative arts and media-based research to prevent smoking and cancer.

The forum also heard about the ‘Talking about Smoking’ project among the Yolngu people of East Arnhem Land. You can read more and watch a video about it here.

Researcher Moana Tane said the Yolngu were introduced to tobacco by Macassan traders and “traditional and cultural factors have contributed to normalisation of smoking”. Narali (tobacco) is celebrated and viewed as an essential part of culture, although interestingly most in the community are happy to have smoke-free homes.
There was a need to consider “very carefully” how to intervene, not wanting to offend and denigrate a cultural relationship built up over hundreds of years, but also to be confident offering support because it is what the community want.

And then it was game time. Maori Public Health Professor Marewa Glover explained she wanted to find a way for Aunties to support young pregnant Maori smokers to quit, so she developed a board game to help them deliver essential messages on smoking, nutrition and antenatal care.

Like a Snakes and Ladders game, it’s based, she said, on Robert West’s theory of addiction, where quitting smoking is not a straightforward journey. It has ‘low dice’ cards to connect with low motivation days, and ‘high dice’ cards when smokers are more likely to listen to quit messages. The snakes represent relapse.

“The Aunties were much more interested in playing a game than having me stand and lecture,” she said.

The feature image is from the Keep it Sacred website.

Watch Professor Tom Calma talking about the harmful impacts of “stop start” government policies for the health of Aboriginal and Torres Strait Islander people.
Marie McInerney writes:

Some of the strongest and most powerful experiences and learning opportunities at the recent World Indigenous Cancer Conference in Brisbane took place in the conference’s Yarning Circle.

You couldn’t miss it. The Yarning Circle was marked out in the main conference space by striking Aboriginal and Torres Strait Islander artwork and floor rugs, providing a safe and welcoming space on Jagara country for Indigenous Elders and delegates at this inaugural international event.

Each day, Elders like Reg and Rose Crowshore 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.
They came to share stories and knowledge alongside the wider conference program. Like the conference sessions, there were presentations on prevention, cancer screening, and support for patients.

But it was the Yarning Up open forums that had everyone talking, in and outside the Yarning Circle.

Often there were sobs, other times screams of laughter, every now and again a powerful song could be heard in the session rooms across the other side of the hall.

**For many it was the highlight of the conference.**

One delegate stood up towards the end to say how “very privileged” he had been to be able to sit in on the circle, and hear stories from Elders from across the world.

He said that being in the Yarning Circle had probably had more of an impact, more of a benefit for him in his work than in hearing the more scientific or academic presentations in the conference program. “It’s been an absolute blessing,” he said. “I really do appreciate it.”

Yarning circles are common in many First Nations gatherings and communities, and are becoming now a feature of major Indigenous conferences.

As conference organiser Associate Professor Gail Garvey from the Menzies School of Health Research said, Yarning Circles provide a safe place for Indigenous people to share stories around strength, resilience and hope – and shouldn’t just be confined to Indigenous conferences.

Susan Forrester from VACCHO credits the International Indigenous Working Group on HIV & AIDS as pioneering them at conferences. She was involved with the creation of a First Peoples Networking Zone in 2014 at the World AIDS conference in Melbourne.

“Community people were finding there wasn’t really a place for them to have a voice (at conferences),” she said.

“As we know with conferences, we need the data, the clinical side, the academic side, but pushing for a place for community is really important.” It needs to be grounded in local culture, she said.

**Yarning in research**

According to publications by Aboriginal researcher Dawn Bessarab, Indigenous people across Australia refer to and use ‘yarning’ in the **telling and sharing** of stories. It’s an oral tradition also well known and respected in other Indigenous nations.
Bessarab provides a case study in a seminal researchers’ guide produced by the Lowitja Institute which talks about how yarning could be applied as a rigorous research method and describes the different types of yarning that took place in a project she was involved in:

- Social yarning (before the topic yarn, when a connection is established and trust is usually developed).
- Research topic yarning (relaxed but purposeful, to gather information related to the research topic).
- Collaborative yarning (sharing information, exploring ideas in explaining new topics, leading to new understandings).
- Therapeutic yarning (when the participant discloses information that is traumatic, or intensely personal and emotional).

Dr Angeline Letendre, Lead Scientist of the Community Research Stream at the Alberta Cancer Prevention Legacy Fund in Canada also spoke to the role of story-telling in indigenous communities: if something is repeated enough, it goes beyond anecdote and information, she told the conference.

“Our stories are not just narrative, they’re evidence,” she said.

Here are some other thoughts from delegates about the #WICC2016 Yarning Circle, or what they wanted to share there, and some pix and tweets below.

**Jerome Yellowdirt**, from the Alberta First Nations Information Governance Centre, told the final session it had been “an honour and pleasure” to be among the Elders in the Yarning Circle.

He talked about his journey with colon cancer, of finding the right treatment through a balance of traditional and “newcomer” ways. “There’s a lot of concern in our homelands about this deadly disease but a lot of ways we can deal with it, live with it,” he said.

Just as pressing, he said, was the suffering their grandchildren were experiencing as they struggled to resist alcohol and drugs. “They’re the ones hurting right now, they’re hurting big time,” he said.

**Amanda Paterson**, an Indigenous Health Project Officer, was blown away by a session run by the Canadian First Nations elders.

”They did a ceremony to cleanse you of all pain and suffering, to make you more comfortable to talk about things, and to accept the information that was being received. They talked about how they use both types of medicine, traditional and Western, and how that’s worked for them, then we talked about other people’s experiences of cancer and how they’ve dealt with the process. For some, death came really quick, others have been on long, often ongoing healing processes.”

“I have to say this is probably the best part of the conference, talking about individual people and their experiences. I think that has had such a big effect on people (attending) and the way they see their roles going forward.”

It had changed her thinking on how to increase cancer screening rates for Aboriginal people in her community.
“At first I thought we’d do a big health promotion, now I’m thinking we do yarning circles with community people. Even if there’s only 10-15 people, the flow on effect will be amazing. Hearing from another person what they could have done to prevent cancer I think will have more of an effect than having a poster on a wall.”

Aunty Robin Payne is an Aboriginal woman from Dubbo and a cancer survivor who is on the 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.

“I was reared up in a white town. We just played like the white kids, though she got called names, of course, like ‘Vegemite’ and ‘Gravox’. And the teachers didn’t want to teach you, so they put us at the back of the room with our hands on our head…”

Being part of the Yarning Circle had been enlightening, she said. “It’s bringing us closer together, all having our say, telling our stories.

Yarning Circle MC Brian Arley, from the Menzies School of Health Research, was thrilled to have Apunipima Cape York Health Council CEO Mark Wenitong tell the conference dinner he had learnt more about the lived experience of cancer in the Yarning Circle than through his academic learning.

“It was terrific, it actually worked out better than we expected in that it really was a Yarning Circle, it was a welcoming space, a culturally safe space for Aboriginal and Torres Strait islander people and First Peoples from overseas to share their stories,” Arley said. “That’s the strength and beauty of it.”

For him the most powerful moment was the day before the conference began, when Elders from across the world came together for a cup for tea: “I thought this is it, this is why we’re here.”

For Susan Forrester from VACCHO, a powerful moment came when a health promotion officer from a large organisation presented to the Yarning Circle on a selection of health promotion resources and ideas to target Indigenous people in screening.

It was a very welcome initiative, she said, but then a question came up. “It was a beautiful and very important question, and I think a question that wouldn’t come up in the conference: ‘Do you have anyone who is Aboriginal and Torres Strait Islander working with you?’”
“The answer was ‘no’. And then this flood of support came to this young person: ‘If you walk beside us, if you have Aboriginal people working with you, we’ll all be able to close the gap together; if you need support higher up within the organisation, we Elders will support you’.

“I was jumping up and down in my seat,” she said. “This is the kind of business that takes place in the Yarning Circle, this is about culture, this is about cultural ways.”

“The Yarning Circle is where the real business is done,” she said.

Watch this interview to hear more about the Yarning Circle.

Some more tweets about conference spaces
You can track Croakey’s coverage of the conference here.

Sharing some powerful stories from a Yarning Circle – “where the real business is done”

#WICC2016
Marie McInerney writes:

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 told the recent World Indigenous Cancer Conference in Brisbane 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.
Her research has shown that Maori cancer patients have a higher prevalence of comorbid conditions, with around two and a half times the rates of diabetes, heart failure, respiratory disease and renal disease seen in non-Maori patients.

“Maori and other Indigenous populations have high rates of comorbidity, those with comorbidity are less likely to get treated, and those who do get treated do better,” Sarfati said. “This then opens up a pathway where we can intervene to improve cancer outcomes and to reduce inequities between Indigenous and non-Indigenous patients.”

Sarfati is director of the Cancer Control and Screening Research Group at the University of Otago. Her plenary address at the conference was: Uneven playing fields, how pathways of care and comorbidity result in inequities in cancer outcomes.

In response to recent research published in The Lancet Oncology, which she reviewed, on the scale and profile of cancer in indigenous peoples of the US, Canada, Australia and New Zealand, Sarfati called for a strategic focus on the burden of cancer among Indigenous people, the need for better monitoring and interventions that address the underlying factors driving cancer inequities.

She said the Lancet study’s most striking finding relates to the high incidence of potentially highly preventable cancers, especially those strongly related to smoking (such as lung cancer) and chronic infection (including stomach and liver cancers) among Indigenous people.

But, she told the conference, Indigenous people also have different treatment and diagnostic experiences along the cancer continuum.

She outlined 2010 research that highlighted inequities in colon cancer survival, where Maori patients had a 30 per cent worse survival than non-Maori patients. Comorbidity and treatment/health service factors each accounted for a third of the survival difference.

**Ethnic inequities in colon cancer survival**

Comorbidity and treatment/health service factors each accounted for a third of the survival difference.
Sarfati said: “At each step along the treatment pathway, there were little differences, always to the disadvantage of Maori patients.”

She described the effect:

“What you can see is that Maori patients with bowel cancer requiring chemotherapy treatment were just a little bit less likely to be referred to the oncologist. If referred, they were just a little bit less likely to be actually reviewed by the oncologist. If reviewed, they were a little less likely to be offered chemotherapy. If offered it, a little less likely to receive it, if they received it, a little less likely for that to happen within the recommended period...So at each step, the differences were small but the cumulative effect becomes quite large.”

This was not an isolated example. Sarfati pointed to other research that has shown Maori lung cancer patients were four times less likely to receive curative rather than palliative cancer treatment compared with Europeans, “even after adjusting for age, gender, deprivation, comorbidity, tumour type, stage, and whether or not patients declined management.”

“The authors of that study concluded that that sort of difference in receipt of curative treatment would be enough to expect to see a difference in survival,” she said.

Sarfati said international studies have shown that Indigenous disparities in cancer survival are, at least partially, explained by differences in levels of comorbidity.

For example, research led by another conference presenter, Dr Suzanne Moore, found that excess comorbidities were contributing to lower curative treatment rates and poorer cancer survival for Māori and contributed to the survival disparity among Indigenous people with lung cancer in Queensland.

It notably found that Indigenous people with lung cancer and diabetes had 40 per cent worse survival than Indigenous people without diabetes when the presence of diabetes was unrelated to survival in non-Indigenous people.

**So what is the comorbidity effect?**

According to Sarfati, part of the effect of comorbidity on cancer survival is due to the excess physiological demand on patients with comorbidity.

“Patients with serious illnesses and cancer are likely to fare worse as a direct effect of those illnesses on their life expectancy,” she said. “We can’t do much about that by the time patients are diagnosed with cancer.”

However, there are, she said, two pathways between comorbidity and poorer survival that we can do something about. In part, Sarfati said, it’s where some comorbidities may have a direct effect on cancer progression. For example, patients with poorly controlled type 2 diabetes tend to have high levels of insulin and other factors which can actually promote cancer cell growth.

But also, importantly, those with comorbidity are substantially less likely to get curative treatment than those without comorbidity. “This is a really strong effect and we see it regardless of which cancers and which treatment we look at,” she said.
There are a number of reasons for this, not least concern by a clinician that treatment may be less effective for patients with comorbidity, or that patients with comorbidity might not be able to tolerate surgery or chemotherapy and may be more likely to decline treatment.

“But underlying these is the assumption that the harms of treatment for patients with high comorbidity outweigh the benefits,” she said. And that, she said, is largely guess work because patients with comorbidities are usually excluded when randomised trials are done.

In fact, she said, high quality studies consistently show that those with similar levels of comorbidity do better when they are treated than those who are not.

**Ground-breaking research**

With those studies in mind, 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 some of the medication that patients are on can be reduced to reduce the risk of toxicity from chemotherapy
3. evaluation of mental health, with a particular focus on depression, given good evidence that shows 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.

“The ultimate aims are to improve outcomes for cancer patients with a particular focus on reducing inequities between Maori and non-Maori cancer patients,” she said.

Addressing comorbidity is one promising area of intervention. However, to address inequities in outcomes between Indigenous and non-Indigenous patients, a whole of pathway approach is needed. She listed factors she sees as important:

1. A stated commitment to achieving equity, at a high political level.
2. Health care leadership that includes Indigenous people so solutions make sense to Indigenous people.
3. Health system organisations which have processes and systems to ensure access, so that each step of the system is considered from an equity perspective.
4. Really explicit treatment standards “so we know we’re doing what we think we’re doing”
5. Really good data collection, analysis and reporting.
6. A health workforce that reflects the community it serves and is culturally competent.
Her take home messages were two-fold: “One, addressing inequity within health care services means a whole of pathway approach and secondly, addressing comorbidity may be one pathway through which we may be able to address inequities.

And she shared this fabulous quote: “Epidemiology: people’s stories with the tears wiped away.”
“I am not a doctor, I am not a nurse’

The conference also heard of two projects that aimed to capture and understand the voices of Maori cancer patients and survivors, and how they felt about the health systems that they interacted with.

Tira Albert from the Mana Wahine Maori health service talked about the Cancer Stories of New Zealand research project, in which Maori patients talked about a lack of cultural awareness from health care professionals and that what got them through was often outside the system.

For many, she said, it was a case of communication, language and health literacy.

One patient welcomed the explanation from a surgeon that Grade 3 cells were “more lion than pussy cat”. “I found this useful language to explain to friends,” he said.

Another was not so lucky:

“When the doctor told me it was grade 3 – I said oh that’s good, does it go up to ten and he said no grade 4 is terminal...[I] sat there like a stunned mullet then cried and cried in car park.”

There were similar strong messages in the ‘This strange world that is cancer’ project that explored disparities in health care between Maori and non-Maori New Zealanders.

Cheryl Davies from the Tu Kotahi Maori Asthma Trust said patients appeared reluctant to complain about care, but needed interventions that made the world of cancer “less foreign”, ensured health professionals used clear and understandable lay language, and “nestled in” culturally appropriate services, such as a Maori ‘navigator’ of the health system.

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Some tweets from the conference
NZ research aims to improve outcomes for Indigenous peoples with cancer

#WICC2016

You can track Croakey's coverage of the conference here.
What are the ways forward from the inaugural World Indigenous Cancer Conference?

Marie McInerney writes:

The inaugural World Indigenous Cancer Conference was a rare opportunity for Elders and Indigenous delegates from across the globe to share diverse experiences of cancer, as well as their work in research, policy, practice and communities.

While experiences differ across Indigenous communities, there was a unified call for better and consistent data, more specialist Indigenous health care workers, better cultural understanding and practice in health settings, and improved engagement with communities. There was also much interest in Indigenous ‘navigators’, like the Native Sisters in the United States.

Below are final reports on presentations, as well as feedback from some participants on their conference highlights.

You will also find a selection of conference tweets (see the final analytics at the end of the post – with more than 10.5 million Twitter impressions and 600 participants on Twitter).
Hostile environments

“Discrimination is literally killing Indigenous and other disadvantaged minorities around the world and we now have global data documenting that.”

As Croakey previously reported, Harvard Public Health Professor David R Williams talked about the impact of implicit bias and institutional racism in a workshop ahead of the conference.

In his plenary address, he looked at the broader impact of race and racism on health, documenting how racism creates conditions of life that can lead to racial and ethnic differences in cancer, as well as other diseases.

This can be seen most obviously in the environments in which many minority groups live: the segregation of black communities in the US and the forced removal of Indigenous populations across the globe, he said.

“Where you live matters profoundly for your health,” he said. “Your postal code is a more powerful predictor of your health than your genetic code.”

Williams highlighted one study that showed heart failure before the age of 50 was 20 times more common in blacks than whites in the US, and said there is enormous scientific interest in evidence of accelerated ageing of black Americans “at the cellular level”.

Research had found higher rates of breast cancer among black women aged under 40 in the US, West Africa, United Kingdom and the Caribbean. “Could it be that black women in different contexts are exposed to very similar adverse conditions that drive the differences we see?”

While social economic status plays a role, Williams said evidence is growing that there is “an added burden of race”, which has been explored most compellingly by US Public Health Professor and researcher Arline T. Geronimus as “biological weathering”.

“We are documenting now that repeated exposure to psychological, social, physical and chemical stresses in work and living environments and the greater clustering of these stressors are literally biologically weathering our populations.”

And, he said, there are more signs of long-term and intergenerational effect. Research had shown that a few stressful experiences in the lives of adults did not predict cancer risk; however, traumatic earlier experiences – such as abuse as a child by someone close, the death of a mother, or chronic depression while growing up – are predictive of cancer risk.

“There is growing evidence that early life exposures shape health profoundly,” he said.

In good news, he highlighted a state-wide cancer control program in the US state of Delaware that over less than ten years eliminated screening disparities, equalised incidence rates, and nearly closed mortality rate gaps.

The keys? Special outreach efforts for minority populations and the provision of nurse navigators.

Williams concluded: “Inequalities in health are not acts of God, they are not random effects, they reflect the successful implementation of social policies. Improving health requires political will to make a commitment to new strategies that will dismantle policies that create inequality and that will provide opportunities for health for all.”

Watch an interview with Professor David R Williams.
Way beyond individual choices

“If something is repeated enough, it goes from being information to evidence. Our stories are not just narrative, they’re evidence.”

Dr Angeline Letendre from the Alberta Cancer Prevention Legacy Fund in Canada also talked about the physical, social and psychological environments in which Indigenous peoples live, and yet how they are still blamed for not making the “right” personal lifestyle choices.

She said:

“There’s always that element of choice, always of blame...when you’re talking about modifiable risk factors, you need to understand what are the contexts for Indigenous people.

What does it mean for an Indigenous person to be physically active? Stress is not really included as a modifiable risk factor for cancer (so how do we) think about accumulated stress/trauma in Indigenous communities?

The WHO (World Health Organisation) calls access the number one determinant of health for Indigenous people. It’s also about access to clean water, safe community, not just to health care.

People are really suffering in our communities, many times cancer is just one issue they’re dealing with. If you don’t feel safe in a community, you’re not going to be out there being physically active. I don’t know if I’ve ever seen a Reserve with sidewalks. We need to be more inventive.

We need multiple strategies, programs and plans. One thing is not going to work.

If we don’t do work or develop programs that are meeting (community) needs and that they’ve been involved in developing, we are probably not going to have any more success than programs have in the past.

“We can talk about trauma-informed care all we want, but if we don’t have a sense of where some of that trauma originates, it’s not making sense.”

Her presentation stood in marked contrast to the messaging from Cancer Australia’s new Cancer Lifestyle Check, which has been critiqued for failing to address the social determinants of health.

Best or worst case scenarios?

“This is a black space, this is an Indigenous space...”

Romlie Mokak, CEO of the Lowitja Institute, told the closing plenary about a collaborative project the research organisation had undertaken in 2013: ‘The shape of things to come: visions for the future of Aboriginal and Torres Strait Islander health research’.
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.”

Next steps

“We know there are many challenges and barriers, but let’s share the enablers, what are some of the positive things, what have we been actively doing to make change, how are we strengthening our communities, supporting cancer survivors?”

Conference organiser Associate Professor Gail Garvey from the Menzies School of Health Research said she was confident it had lived up to its theme and purpose: connecting, communicating and collaborating.
Moves were underway now to establish an international Indigenous cancer network (with hopes for another international conference in two or three years) and to support the development of country specific networks.

She said a key message from presenters was that cancer among Indigenous people has to be seen in the holistic way that Indigenous people understand health, and also to be open and upfront about difficult topics like racism and trauma.

“We have to acknowledge that Indigenous people experience this ‘continual weathering’, of us and our culture and health and wellbeing,” she said.

Garvey said the conference had revealed both commonalities and differences “between us as Indigenous people and the way services operate and deliver”.

It also highlighted the elements of success that weren’t being implemented, including having Indigenous identifiers for monitoring and providing evidence of outcomes (such as with cervical cancer screening in Australia), the need for Indigenous health workforces, and Indigenous patient navigators.

She said: “We know we need to get more of our mob working in cancer care settings.”

What were some of the highlights?

**Michelle Bovill and Yael Bar Zeev, University of Newcastle**

For Bovill, the most exciting part of being at the conference was to meet other Aboriginal researchers to whom she normally doesn’t have access.

The standout presentations for both were by Native American Cancer Research Corporation director **Dr Linda Burhansstipanov**, on the **Native Sisters** ‘patient navigation’ program, on **tobacco control** (a particular interest for Bovill whose work is focused on engaging pregnant Aboriginal women on smoking issues) and on the Walking Forward physical exercise program.

“I love her [Dr Linda Burhansstipanov], to see how she’s designing her interventions, she’s very innovative. I could have sat in the room listening to the work she’s doing all day,” Bovill said.

For Bar Zeev, new understandings of diversity were a great insight, including through some of the cultural highlights of the conference, the markedly different cultural traditions of Aboriginal and Torres Strait Islander dance groups.

“I think meeting so many people who have so much in common yet are so diverse was an eye-opener, that was really good for me as a white researcher.”

**Scott Leischow from the Mayo Clinic, United States**

Leischow said the presentation that really struck him was by Darren Clinch, from the Department of Health and Human Services, on mapping access to healthcare services through geospatial visualisation of barriers and enablers for Aboriginal and Torres Strait Islander people. He said:
"To me, that’s a very powerful approach to be able to understand and drill down in communities, understand what’s going on…. I thought that was really important because that kind of data can help you document what is going on… that’s what you can bring to a policy maker and say ‘if you don’t make some fundamental changes, to the lives of people who don’t have access to fruit and vegies or are exposed heavily to tobacco or don’t have access to good health care, how can we expect their lives to be better?’"

Julie Maria Fresta, Central Queensland, Wide Bay, Sunshine Coast Primary Health Network (PHN)

“I think the highlight for me would have been (Indigenous singer-songwriter) Archie Roach’s conversation with his specialist: that one conversation seemed to pull so many different things that we talked about all week together. Also having had the privilege of seeing him perform the night before was so moving.

When David Williams talked about childhood trauma and research that shows the connection with cancer later in life, (and we) then heard Archie talk about his story (as a member of the Stolen Generation), it brought it all together.”

Uncle Bill Buchanan, National Indigenous Cancer Network (NICaN) ambassador

“The highlight for me was the Yarning Circle, to have the participation of many nations in the circle. Importantly also in that circle we dealt a lot with the experience of cancer survivors, which was also reflected on stage with Archie Roach.”

He said the two different visions for the future outlined by Lowitja’s Romlie Mokak (see above) were also thought provoking.

“I think it’s quite frightening, when you actually reflect on (the worst case scenario), that that’s right where we are today. It’s a very good time for governments to take stock: if they’re going to achieve Closing the Gap (targets), they really have to take responsibility for the current position and embrace a vision that’s going to take us there… I think we’re at worst-case scenario. Is the best case a reality or a dream?”

Dr Alexandra King, Simon Fraser University, Canada (a plenary presenter)

“I was particularly impressed by the commonalities when facing cancer, and by the incredible work that Indigenous peoples in the represented countries have achieved. There is much more to be done, and working collaboratively, so much more is possible.

I see us needing a strong focus on Indigenous leadership within the cancer research and care cascades. I also feel the need of ensuring this is inclusive of all Indigenous peoples – for example, Indigenous healers and knowledge keepers; Indigenous peoples from Central and South America, southeast Asia – and creating appropriate mechanisms and policies to achieve this.

The other way forward for me is a greater focus on Indigeneity in the most positive sense, rather than the focus on colonialism/colonization, racism, and other more negative health determinants.”
Marie McInerney, Croakey’s roving reporter

Menzies researcher Abbey Diaz jumped in a taxi to go home one evening during the conference. The driver asked where she’d been. When she replied, “at the World Indigenous Cancer Conference”, he said, “then you’ll be really interested in what I just heard on the news, that cervical cancer screening rates for Aboriginal women haven’t improved in 20 years!”. The research had been published that day by her colleague Lisa Whop.

Across the conference, lower screening rates for Indigenous people around the globe were an issue, that was seen as closely related to lack of engagement by mainstream health initiatives with Indigenous communities, ongoing Indigenous mistrust of mainstream health services, and the need for community champions and Indigenous navigators to help guide people through the complex and often hostile health systems.

I was struck by one of the recommendations in the Cancer Stories of New Zealand research project for workplace policies, where colleagues can ‘gift’ their sick leave to another colleague who is dealing with cancer.

With financial burden nominated as the biggest worry in a number of ‘unmet needs’ research, it was a measure of the terrible cost to some families and communities of a cancer diagnosis and the role of community.

I was also struck by the irony that the Native Sisters patient navigation program was inspired by Harlem oncologist Dr Harold Freeman, who despaired that black Americans with cancer were not presenting for health care until their tumours were open sores. Yet the conference heard that the first connection many Aboriginal and Torres Strait Islander people have to palliative care may be through hospital emergency departments.

And finally an important warning from BreastscreenWA Aboriginal liaison officer Leanne Pilkington: “Providing access is not engagement.” Watch an interview here.
A selection of conference tweets

@AbbeyDiaz Says: Common theme at WICC2016 is the need for cultural competence in healthcare. Anne-Marie Dewar @MenziesResearch

@Mo_Fin: Shocking increase in disparities in outcomes for Aboriginal people diagnosed with cancer WICC2016

@mariemcinerney: ‘We see things not as they are, but as we are.’ David ‘Tarinda’ Copley on the different lenses through which we all live and work WICC2016
You can track Croakey's coverage of the conference here.

What are the ways forward from the inaugural World Indigenous Cancer Conference?

#WICC2016

Conclusions

- The challenge of a rising cancer burden must be met by an integrated approach of prevention (including early detection) and treatment
- Recent advances in the molecular (epi)genetics of cancer and related tools offer exciting interdisciplinary approaches to cancer prevention
- Research should encompass implementation science and enable translation to effective change for all parts of the population

Abbey Diaz  @AbbyDiaz_says  · 32m
Take home message from Chris Wild at #WICC2016 opening session.

Marie McInerney  @maricmcerney  · Apr 13
This is the take-home from #WICC2016 says Cancer Australia CEO Helen Zorbas, informed Indigenous Cancer Framework
What are the ways forward from the inaugural World Indigenous Cancer Conference?

What is Cultural Humility?

"I believe you understand what you think I said, but I'm not sure you realize that what you heard is not what I meant.”

- Unknown, written on a blackboard in the band hall of the Weagantow Lake Reserve, 380 air miles north of Thunder Bay Ontario.

Slide courtesy of BC First Nations Health Authority
And, finally, thanks to all those who helped to share the #WICC2016 news via tweets and photographs. You helped get #WICC2016 trending.
What are the ways forward from the inaugural World Indigenous Cancer Conference?

Croakey Conference News Service

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Read the Twitter transcript here.