Marie McInerney and Summer May Finlay reported on the Annual NHMRC Symposium on Research Translation co-hosted by the Lowitja Institute and NHMRC held in Brisbane from 14 – 15 November 2017 for the Croakey Conference News Service.

#ResearchTranslation17

Croakey is a social journalism project for health based in Australia.  
http://croakey.org
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Conference preview: Tune in to some important conversations on Indigenous health research

Marie McInerney writes:

Breaking down research and policy silos and challenging the impact of institutional racism and colonisation on Indigenous health research, policy and practice will be at the heart of “courageous conversations” at a major symposium in Brisbane.

The 6th National Health and Medical Research Council (NHMRC) symposium on research translation will focus on Aboriginal and Torres Strait Islander health and bring together leading national and international Indigenous researchers to “join the dots” between research, policy and practice.

The two-day symposium is co-hosted by NHMRC with the Lowitja Institute, the national Aboriginal and Torres Strait Islander health research institute.

Dr Tamara Mackean, a Senior Research Fellow in Indigenous Health at Flinders University and the George Institute for Global Health, said the NHMRC had “embraced” the partnership. Lowitja and the Indigenous-led scientific committee, which she co-chaired with Associate Professor Yvette Roe from the University of Queensland, had developed a “strong global Indigenous presence” in the program.

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

http://bit.ly/2yXFkD1
“So we’ve got the right kind of space, the right kind of coming together of different perspectives and disciplines to really grapple with what are at times quite complex problems but also the barriers to actually getting some of the research findings into policy, into practice and into systems,” she said.

Mackean said silos existed in non-Indigenous health research too but there were fundamental differences for Indigenous researchers in terms of “health and wellbeing as lived and understood by Aboriginal and Torres Strait Islander people and from the systems and practitioner perspective”.

Focus on innovation

Keynote speakers at the event included Professor Ian Anderson, Deputy Secretary for Indigenous Affairs in the Department of Prime Minister and Cabinet, and Donna Ah Chee and John Paterson from the Central Australian Academic Health Science Centre.

Dr Carrie Bourassa, a Meti researcher from Canada who was recently appointed as the Scientific Director of the Canadian Institute of Aboriginal Peoples’ Health, spoke on systemic racism and its impact on health, canvassing unethical research and the historical legacy of colonisation.

Her fellow international keynote Sir Mason Durie, one of Aotearoa New Zealand’s most highly respected academics, spoke about the potential for great innovation at the interface of different knowledge systems.

A panel session titled Courageous Conversations and featuring Dr Jaquelyne Hughes, Dr Ray Lovett, Prof Alex Brown, Dr Chelsea Bond and Dr Cass Hunter looked at how Indigenous health research still takes place within “an overarching system that is still inherently colonial”, Mackean said.

She expected it to be one of the standout discussions at the symposium.

“What is courageous is not just about Aboriginal and Torres Strait Islander people standing up and saying we want to have a conversation about what colonisation means within contemporary settings in terms of what we are all trying to do to improve health and wellbeing,” she said.

“It also allows for non Aboriginal and Torres Strait Islander people to really understand what is their place in this research space. And that starts to open up even more challenging ideas: issues of racism and whiteness and privilege.

“These are very difficult things. When you talk about them people automatically shut down, because they are foreign, they feel frightening, they feel bigger than Ben Hur.”

Road map and road blocks

The symposium came soon after the release of the NHMRC’s Draft Road Map 3 to provide NHMRC’s strategic direction for Aboriginal and Torres Strait Islander health and medical research over the next ten years.

It includes a commitment to continue directing five percent of its annual budget to Indigenous research and notes that community consultations viewed public health issues rather than medical advances “as particularly important”, it says.
The draft, which was open for comment until December 10, acknowledges the role of institutional racism “as a factor that impacts on health service delivery” and of the “ongoing importance of research into the social and cultural determinants of health as well as health system, service delivery and translational research”.

But the research event was also being staged as Australia hit a roadblock on the path to self-determination, with the Turnbull Government’s rejection of a key element of the Uluru Statement from the Heart for a nationally recognised body to give Aboriginal and Torres Strait Islander people a Voice to Parliament.

One of the architects of the Statement, senior Indigenous health advocate Pat Anderson AO, is the chair of the Lowitja Institute, which last year hosted an international conference of Indigenous researchers in Australia.

The conference released a closing statement declaring that: “The right to self-determination underpins the right to health.”

It called for Indigenous thinking, intellect, and wisdom to be valued and for the research process to be decolonised.

Both Mackean and leading non-Indigenous researcher Professor Fiona Stanley told Croakey that the Voice proposal has major significance for Indigenous health and health research.

Mackean said Indigenous knowledge systems, embedded in enduring relationships with the natural environment, had “spawned amazing understandings, not just about health and wellbeing, but science, meteorology, conservation and land management”.

“If you recognise sovereignty you not only recognise sovereign rights but also recognise sovereign knowledges,” she said.

“At some point, be it researching around Indigenous health and wellbeing or policy making around Indigenous health and wellbeing or trying as a society to reconcile what it is to heal, at some point that conversation about sovereignty and proper recognition will be had.

“You can only meet problems borne of clashing knowledge systems by properly understanding the knowledge systems.”
On the Uluru Statement and Indigenous health

Q & A with Professor Fiona Stanley

Q: What are the health implications of the Voice proposal?

Fiona Stanley

There are three major implications:

1. Giving First Nations the power to influence the services and policies in health and other areas that influence health such as housing, environments, education, culture, etc results in much more effective services than those that are imposed. The latter mostly do not appreciate the First Nations history, intergenerational trauma and current circumstances and ignore really important local knowledge that could make considerable differences to use of services, their trust by First Nations peoples and their ability to prevent and treat diseases.

2. Those communities and populations which have more power (examples below) also have fewer mental health problems, substance abuse, domestic violence and child neglect.

3. Giving First Nations people a voice is, like renewables with climate change, more cost effective than not doing so, not only for health services, but for most aimed at wellbeing and welfare. If governments only care about financial bottom lines, a First Nations voice is the way to go.

Q: What are the implications of the Voice proposal for research translation?

Fiona Stanley

Having a First Nations voice should include empowering First Nations researchers, policy makers and service providers to conduct their own research, analyse and interpret their own data and translate it into improved outcomes.

The recent Indigenous Data Sovereignty symposium at the University of Melbourne (Croakey ed: see this report from that symposium) presented evidence that when this happens, the outcomes are spectacularly better!

Most Indigenous health research conducted by First Nations researchers is very applied and usually answers the questions about what works and what doesn’t and what are the characteristics of Indigenous services that work. Such research is immediately translatable. Such research is done with passion and cultural integrity and means that not only will services be used, they will build pride and combat racism.
Q: Could you give any examples to illustrate the issues raised above?

Fiona Stanley

Yes, there are a lot from both overseas and in Australia.

Two Canadian studies (British Columbia and Nunavut):

1. Chandler and Lalonde studied all the tribal tracts across British Columbia and collected youth suicides over a 25-year period. There was huge variability in these rates, some tracts had the highest in the world and others had no suicides at all! The characteristics of those with low rates were a) Aboriginal controlled services; b) language; c) treaty or treaty negotiations even if they had failed; d) more women on council.

2. In the Nunavut community they negotiated with Health Canada to bring back traditional birthing to this remote northern community which had high rates of substance abuse, domestic violence, suicide, child maltreatment, mortality rates, 60 percent caesarean section rates with women being sent 600 kilometres south to have their babies.

With First Nations control of health services in close partnership with Canada Health, there was a dramatic turnaround in all these outcomes.

Australian examples include Aboriginal controlled health services (we do need better data on these) and other community based, data driven activities in Bourke (Maranguka Community Hub – also improved justice outcomes), Shepparton, Yorta Yorta Data Unit, Fitzroy Valley (June Oscar, Marilyn Carter, Maureen Carter, Olive Knight), and of course the Tiwi Islands chronic disease project. A range of projects run by First Nations researchers in Western Australia have preliminary data on using Indigenous knowledge and elders to vastly improve Aboriginal attendance for care etc.

Q: Are there any other comments you would like to make about the Voice proposal and the Uluru Statement?

Fiona Stanley

Yes. Not only have we wasted millions of dollars on ineffective health and other services which fail to understand causal pathways, but these failed services have actually caused considerable harm (not just wasteful and useless which is bad enough).

Failure is usually attributed (insinuated) to First Nations people themselves rather than the inappropriate and inadequate services provided. This contributes further to the low self-esteem and mental health problems, as well as ensuring pathways to non-participation and incarceration. Giving First Nations a voice is urgent and important for all these and many other reasons. It is the most humane and cost effective solution to closing the gap but will take a huge change in the culture of federal, state and local government bureaucracies. Bring back ATSIC I say!
Conference preview: Tune in to some important conversations on Indigenous health research

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

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Conference preview: Tune in to some important conversations on Indigenous health research

#ResearchTranslation17
Indigenous health leaders call for support for Uluru Statement and a secure future for premier research institute

Marie McInerney writes:

Leading Aboriginal health experts have called on researchers, academics, universities, research institutions and private corporations, especially those with Reconciliation Action Plans, to make a stand in support of the Uluru Statement from the Heart.

Central Australian Aboriginal Congress CEO Donna Ah Chee and Aboriginal Medical Services Alliance Northern Territory (AMSANT) executive director John Paterson made the call at a National Health and Medical Research Council (NHMRC) symposium in Brisbane.

Paterson and Ah Chee, who play key roles in the acclaimed Central Australia Academic Health Science Centre (CAAHSC), urged the symposium, opened earlier by Indigenous Health Minister Ken Wyatt and NHMRC CEO Professor Anne Kelso, to issue a formal statement supporting the Uluru document.
The symposium also heard from a senior Federal Indigenous health bureaucrat, Professor Ian Anderson, about plans to “refresh” Closing the Gap targets. He said the current targets – some of which are due to expire next year – were developed in a “closed shop” that excluded Indigenous experts and communities and fed too much into a deficit narrative.

The NHMRC research translation symposium, its sixth, is this year focused on Aboriginal and Torres Strait Islander health and is co-hosted with the Lowitja Institute, Australia’s National Institute for Aboriginal and Torres Strait Islander Health Research.

Lowitja Institute chair Pat Anderson was one of the architects of the Uluru Statement.

In a keynote address on the work of the CAAHSC, Paterson said Pat Anderson’s connection to the scholars and researchers in the room gave added impetus to the call for the conference to support the Statement.

“Given that Pat Anderson is the chair of Lowitja and led the process that led to the Uluru Statement, it would be appropriate for this broad gathering of the research community to express its support for the Voice of Aboriginal people as reflected in this wise and beautifully crafted expression of self-determination,” Paterson said.

“We cannot let this vision wither on the vine and we need to recognise the ultimate importance of a national voice at this level to protect and safeguard all expressions of community control.”

Ah Chee said Aboriginal and Torres Strait Islander people had been told on multiple occasions by government to work out what they wanted – only to get, as Pat Anderson had said, “a kick in the guts”.

“What we’re calling on the academic and research fraternity of today is to get behind what the Uluru Statement stands for and what the Aboriginal leadership is calling for.”

A range of non-Indigenous researchers, clinicians and service providers, led by Professor Fiona Stanley, are also calling for the Federal Government to support the Uluru Statement.

Paterson said it was also important for the corporate sector – “all those with RAP plans incorporated into their organisations” – to step up in support for the Statement.
Call for funding certainty

In a hard-hitting presentation and later interview with Croakey, Paterson and Ah Chee also called for dedicated NHMRC funding to be guaranteed for the Lowitja Institute.

The Institute, named in honour of its patron Dr Lowitja O’Donoghue, is funded by the Australian Government Cooperative Research Centres (CRC) Programme. It has survived on short-term funding grants or agreements for 20 years, with its latest cycle due to end in 2018.

Ah Chee said the Lowitja Institute was “the torchbearer for Aboriginal health research”, with its predecessor bodies the first health research organisations in Australia to include Aboriginal community controlled organisations as equal partners.

“It’s just not good enough that we have our iconic, leading national research institute... that guides and oversees us in terms of strategic research in Aboriginal health have to constantly worry from triennium to triennium where its next dollar is coming from,” she said.

Ah Chee called for the 400 plus delegates at the symposium to also pass a resolution calling for the Lowitja Institute to get access to ongoing, sustainable funding from the NHMRC.

The two Northern Territory leaders also sounded a warning to the Northern Territory and Federal Governments ahead of the handing down of the findings of the Royal Commission into the Protection and Detention of Children in the Northern Territory.

“We will not sit on our hands and watch this report be put onto bookshelves to gather dust like so many other reports,” Paterson said.

Aboriginal organisations in the Northern Territory would be “vigilant”, to make sure that Federal and Territory governments, which both supported the Royal Commission, committed to its findings, he said.

Focus on aspirations

Also at the symposium, Professor Ian Anderson, Deputy Secretary of Indigenous Affairs in the Department of Prime Minister and Cabinet, urged delegates to get involved with the Council of Australian Government's Closing the Gap refresh over the coming months.
Anderson is a Palawa Trowerna man from the Pyemairrenner mob in Tasmania, with many decades experience in Indigenous health, including as Director of Research for the Lowitja Institute and related Cooperative Research Centre for Aboriginal Health.

He said the Closing the Gap refresh was “an incredibly important process”.

Anderson said the annual Closing the Gap statement by the Prime Minister to Parliament each year had “brought Indigenous policy back to the centre of the national stage”.

But he said the refresh acknowledged “a number of other things we’d like to do better this time”.

Even though the original 2008 targets had been built on the Close the Gap campaign led by Indigenous agency and organisations, he said they had been essentially determined in “a closed shop”, “a conversation between governments”.

“This time we are committed… to Indigenous engagement process as a part of this engagement,” he said, acknowledging many groups like Congress have done considerable work already.

The first round tables with Indigenous communities began two weeks ago, he said, and there would be engagement with Indigenous stakeholders, communities, and leaders over the next few months.

Another key point to learn from the past targets was “to really understand: have we got the balance of science and politics in setting targets?” Anderson said.
While not specifying particular targets, it was hard to understand a rationale for how some of them had been set – “some were not only ambitious but unachievable if you had a good sense of the science behind the target,” he said.

Having the Prime Minister standing up year after year and admitting Australia was not on track with the majority of the targets “reinforces a sense in the broader Australian community that things aren’t working, that all the money we’re spending on Indigenous affairs is not making a difference”.

“It could be true that we haven’t put the right investments behind some of these targets,” he said. “But equally true we probably haven’t set the right targets.”

Anderson signalled the next set of targets would also focus on Aboriginal and Torres Strait Islander “aspirations”, not just feed into a deficit narrative.

While he said nothing was yet fixed, he expected 8-10 targets, with some to address environmental and economic issues.

He said:

*One of the things we’re very mindful of is very fair criticism... that the targets really focus on disadvantage – which they needed to do, but they fed into a deficit narrative that rendered invisible all the success we know is in the Indigenous world.*

*We know that success is there, that’s part of our everyday reality but we don’t reflect that in our targets.*

*Moving to a strengths-based focus is very challenging, because you don’t want to lose focus on the important challenges – there is a gap in life expectancy and we need to have that as part of the targets.*

*We don’t want to lose sight of disadvantage, but we need to shift the narrative, to build a strengths-based approach.*

**Supporting local decision making**

Anderson talked about the importance of good evidence and evidence translation for Closing the Gap, saying his unit was looking to build investment in infrastructure to support regional and local decision making the provides “the granular data they need to make a decision”.

He talked particularly about work done in regional Shepparton in Victoria by the Algabonyah Data Unit established by the Kaiela Institute for the Yorta Yorta people. The work was also highlighted at a recent *Indigenous Data Sovereignty symposium* in Melbourne.

“You need to know how many jobs, in actual numbers, to reach parity, (in order) to go lobby the local businesses and authorities, how many kids, in actual numbers, are missing out on finishing school, how many mums are missing prenatal care, then you can anchor accountability throughout the whole system,” he said.

But evidence was not enough, it needed also to consider Indigenous priorities and cultural preferences and to think how to translate evidence into meaningful information and communicate it effectively so people at the policy level and on the ground could make decisions.
To that end, Anderson announced he was working on an Indigenous research hub, not to do research but to focus on knowledge translation, to bring together policy makers, researchers and Indigenous communities.

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

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Indigenous health leaders call for support for Uluru Statement and a secure future for premier research institute

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The World Health Organisation defines knowledge translation (KT) as:

"The synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and improving people’s health."

A little star struck. A room full of amazing researchers with a common passion on "researchtranslation17 for our people...wow"

The wealth of knowledge & experience in the room at the @nhmrc & @LowitjaInstitute Symposium is mind blowing. With a collective like this real research translation can occur. #researchtranslation17
Minister Ken Wyatt

I applaud your commitment to bring together so many national leaders to discuss issues that are critical to our nation's First Peoples @KenWyattMP #ResearchTranslation17 @nhmrc @LowitjaInstitut
You can track Croakey's coverage of the conference here.

Indigenous health leaders call for support for Uluru Statement and a secure future for premier research institute

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Donna Ah Chee and John Paterson

Indigenous health leaders call for support for Uluru Statement and a secure future for premier research institute

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“Conference News Service”

Warm thanks to all tweeting #ResearchTranslation17 – the hashtag was trending nationally for much of yesterday.
Indigenous health leaders call for support for Uluru Statement and a secure future for premier research institute
“Fantastic” news – Indigenous health experts welcome the news on #MarriageEquality

Participants in a major Indigenous health research symposium in Brisbane burst into spontaneous applause when news broke of the public’s support for marriage equality.

The importance of the outcome for health is highlighted in the interviews below with Professor James Ward and Romlie Mokak, conducted by Croakey Conference News Service reporter Marie McInerney.

James Ward – @researchjames – said it was “fantastic” news, and an incredible result for young Aboriginal and Torres Strait Islander people, with the potential to help reduce suicides. “Love prevailed in the end,” he said.

Romlie Mokak – @RMokak – welcomed the results as a “fantastic outcome”, noting the importance of human rights for health. “The people have spoken and politicians just need to get on with the job of passing the legislation,” he said.

The interviews were conducted at a National Health and Medical Research Council research translation symposium, focused on Aboriginal and Torres Strait Islander health and co-hosted with the Lowitja Institute, of which Mokak is CEO.
“Fantastic” news – Indigenous health experts welcome the news on #MarriageEquality
#ResearchTranslation17

Listen to Professor James Ward

Listen to Romlie Mokak

Meanwhile, on Twitter...

@researchjames • 2h
Now we’ve voted yes let’s get the Uluru Statement and aspirations done! C’mon Aus @IndigenousX

@LatimoreJack
High-fivin 61.6% of Australia right now. #MarriageEquality🎉🎉🎉
Congratulations. Hopefully your elected government listens to the plebiscite result better than it did our #UluruStatement

You can track Croakey’s coverage of the conference here.
Strong message to Turnbull Government from researchers – support Uluru Statement and Lowitja Institute

Marie McInerney reports:

Leading Indigenous health researchers have called on the Federal Government to accept the Uluru Statement from the Heart “in its entirety” as a crucial step in efforts to address health inequities for Aboriginal and Torres Strait Islander people.

Delegates at the 6th National Health and Medical Research Council (NHMRC) symposium on research translation, co-hosted in Brisbane this week by the NHMRC and the Lowitja Institute, voted overwhelmingly to formally support the Uluru Statement.

The move followed called an earlier call at the symposium for researchers, academics, universities, research institutions and private corporations to make a stand in support of the Uluru Statement.
Putting a resolution to the floor of the symposium, **Professor Kerry Arabena**, Director of the Indigenous Health Equity Unit at the University of Melbourne, said the conference had heard repeatedly the importance of “research being embedded in self-determination” and how “hurtful” it was to have the Federal Government reject the Uluru Statement. (Watch her statement to the conference [here](#)).

Delegates also supported, again by acclamation and overwhelming show of hands, a statement calling on the Federal Government to provide sustainable, recurrent funding for the Lowitja Institute, the national Aboriginal and Torres Strait Islander health research institute.

Read the full statements from the Symposium below.

**Supporting the Uluru Statement**

The participants of the 2017 research translation symposium held in Brisbane note the critical role that local Aboriginal community controlled health services play in Aboriginal and Torres Strait Islander people's health research.

The symposium notes that the Uluru Statement is the ultimate expression of the democratic will of Aboriginal and Torres Strait Islander leaders from the many nations of Australia to find a voice at the national level. Genuine participation in the legislation, policies and programs that are designed to address Aboriginal and Torres Strait Islander disadvantage is required to promote health development and Close the Gap.

The symposium also notes that self-determination needs to be expressed at all levels from local community controlled organisations to the national level.

We therefore call on the Commonwealth government to accept the Uluru Statement in its entirety and put the creation of the Voice to a referendum of the Australian people.

**Sustainable, recurrent funding for The Lowitja Institute**

The participants of the 2017 research translation symposium held in Brisbane acknowledge the role of the partnership between the NHMRC and the Lowitja Institute in working together to support the translation of research knowledge to help Close the Gap in the health of Aboriginal and Torres Strait Islander people.

The symposium notes that the NHMRC has sustainable, recurrent funding from the Commonwealth government but the Lowitja Institute has no guaranteed recurrent funding. This is not an equal partnership but neither institution can maximise the potential for research to improve Aboriginal and Torres Strait Islander health alone.

We call on the Commonwealth government to provide long term, sustainable funding for the Lowitja Institute through a guaranteed appropriation in the 2018/19 budget.
Reflections on Voice

Reflecting on the significance of the Uluru Statement from the Heart for Aboriginal and Torres Strait Islander health, Dr Megan Williams, Senior Lecturer in Aboriginal Health and Wellbeing at the Graduate School of Health at the University of Technology Sydney and a contributing editor at Croakey, said:

- Aboriginal people have much sustained experience in quality, timely and ethical research. Research translation is often built from the outset. Partnerships and community priorities drive the research.

- The Aboriginal health research workforce has grown and offers much to other researchers and disciplines. But the Aboriginal health workforce and scope and amount of research must continue to grow. Needs and gaps particularly about determinants of health risk eroding recent successes. The experience of racism in health services and universities is common and frequent.

- A Voice in Parliament reinforced by the Constitutional change is a logical step. This will lead the growth of the next generation of services and research and related workforces. Non-Indigenous researchers, clinicians and service providers are also calling for this Voice in Parliament and government; their direction and efforts are also limited without better planning.

- Worsening health inequity reflects poorly on all Australians.”

Read Croakey’s previous coverage of the Uluru Statement from the Heart here.
You can track Croakey’s coverage of the conference here.

Watch this interview

Summer May Finlay speaks with Central Australian Aboriginal Congress CEO Donna Ah Chee and Aboriginal Medical Services Alliance Northern Territory (AMSANT) executive director John Paterson about:

• The importance of the Uluru Statement
• The need for secure funding for the Lowitja Institute, and
• Their calls for an Aboriginal community controlled-led response to the findings of the Royal Commission into the Protection and Detention of Children in the Northern Territory – available here.
Stop “stacking your CVs” and ensure Indigenous communities lead research

Marie McInerney writes:

Health researchers and institutions that prioritise publication rates and “stacking their CVs” ahead of the needs of Indigenous communities are perpetuating post-colonial exploitation, a leading Canadian Indigenous researcher says.

Dr Carrie Bourassa told a national Indigenous health research translation conference that fly-in fly-out “helicopter research” and other unethical practices were still exploiting and marginalising some First Nations, Inuit and Métis peoples in Canada.

She said research is an inherently political act and plays a key role in self-determination.

“All of you who undertake research, you’re hunter gatherers,” she told delegates at the 6th National Health and Medical Research Council (NHMRC) symposium on research translation, co-hosted in Brisbane by the NHMRC and the Lowitja Institute.

“It’s your responsibility to act in an ethical manner, to undertake research by, with and at the direction of the community.”
In her keynote address, Bourassa, who is Métis and belongs to the Riel Métis Council of Regina Inc, also challenged the notion and impact of “cultural competence” in the health system, saying it masks inherent systemic racism and there is no evidence that training works — “we don’t have appropriate evaluation models”.

She said racism is the biggest social determinant of health in Canada and is literally “killing” Indigenous people in Canada.

Later speaking to Croakey, she referred to the shocking case of Brian Sinclair, a 45 year old Indigenous man who died while waiting for care for 34 hours in a Winnipeg emergency room.

His tragic death echoed many of the issues raised in the 2014 death in custody in Western Australia of 22 year old Yamatji woman Ms Dhu.

“Be ready to fight”

Bourassa was earlier this year appointed Scientific Director of the Institute of Aboriginal Peoples’ Health, one of 13 organisations that make up the Canadian Institutes of Health Research (CIHR), and the first to be located outside a major urban centre.

Prior to that, she spent 15 years as a professor of Indigenous health studies in the Department of Indigenous Health, Education and Social Work at the First Nations University of Canada in Regina.

She told delegates that gaining academic tenure and taking up her new appointment had raised significant and serious issues for her around ethical research, and how she could ensure that her work “serves community” rather than the institutions for which she works.

That tension came up elsewhere at the symposium, including in one panel session on Courageous Conversations.

Talking about the need to build relationships with communities over time, Bourassa said researchers “can’t expect to walk into a community with a research agreement in your hand and think that is how you build a relationship”.

“It’s an ever-evolving process, it’s not about stacking your CV, not about the number of publications,” she said.

As a result, she said the CV of an ethical Indigenous researcher and/or academic will inevitably have to look “very, very different” to that of another researcher, and will likely create “friction” with their institutions.

The challenge was equally for institutions to be open to find ways other than peer review and publication rates to value research, whether it be the time invested in Indigenous communities, or “what else we’re doing with the community that’s really valuable”.

“It did cause me a lot of disagreement, a lot of negotiation when I came up for tenure, (about) what that would look like,” she said. But she said she fought on.

“My responsibility was first and foremost to the community. If I’m going to bring them into a research project my responsibility is to them first.”
Research as exploitation

Bourassa said there remains “a lot of hesitation” among First Nations people and communities about engaging in research because of Canada’s long and ongoing history of “research as exploitation”.

She gave one terrible example, only relatively recently revealed, about the so-called nutritional experiments on First Nations children in Canada’s infamous residential schools and among adults in remote communities after the Second World War.

As this article reported:

“It began with a 1942 visit by government researchers to a number of remote reserve communities in northern Manitoba…

They found people who were hungry, beggared by a combination of the collapsing fur trade and declining government support. They also found a demoralized population marked by, in the words of the researchers, “shiftlessness, indolence, improvidence and inertia.”

The researchers suggested those problems – “so long regarded as inherent or hereditary traits in the Indian race” – were in fact the results of malnutrition.

Instead of recommending an increase in support, the researchers decided that isolated, dependent, hungry people would be ideal subjects for tests on the effects of different diets.”

Bourassa gave other more recent examples, including:

• Biological samples obtained and removed from communities without consent, such as from the Nuu-chah-nulth community in the 1980s – specimens, which according to this 2002 Nature article, “yielded half a dozen published articles”

• Traditional knowledge shared by Knowledge Keepers, Elders, and Healers that was appropriated without the knowledge or consent of the community, including to develop pharmaceutical products

• Human remains and cultural property taken for storage, display in museums, or sale

• Poverty stricken communities feeling “beholden” to participate in research because it could bring in money and jobs.

See Bourassa’s slide on the next page on some common grievances that she said continue to have an impact.

Bourassa said:

We have some researchers go into the communities, basically take out that knowledge and use it for their (own) benefit.

If often happens without them meaning to, but well-meaning or not, it still impacts our communities and causes many issues, mostly for them to see research in a negative way.”

Bourassa outlined a set of standards developed in Canada by the National Steering Committee of the First Nations Regional Longitudinal Health Survey in 1998 that established how First Nations data should be collected, protected, used, or shared.

They are known as OCAP – standing for ‘ownership, control, access and possession’ – and were created because there was no law or concept in Western society that recognised community rights and interests in their information.
In line with work being done in Australia and New Zealand towards Indigenous Data Sovereignty, the National Steering Committee (now the First Nations Information Governance Centre) said in 2004 when the protocol was developed:

First Nations’ claim to ownership of their own data is not some strange new aberration. On the authority of their own institutions and laws, governments and academics have long possessed and owned data without really thinking twice about it.

OCAP brings the illegitimate owners into the spotlight. Those who most strongly reject the notion of data ownership tend to have control or possession of considerable volumes of it.”

It is, Bourassa said, “a self-determination approach” to research, where communities can say ‘this is the type of ethical engagement we expect’ and it’s an approach that she says has worked in all her research.

But it is not mandated by the Tri-Council Policy Statement on ethical conduct for research involving humans (see Chapter 9 specifically on Indigenous people), a joint policy of Canada’s three federal research agencies including the CIHR.

The Tri-Council itself has “absolutely no teeth”, Bourassa said – meaning it effectively sends a message to researchers that “you should have a research agreement and a data agreement, but you don’t have to”.

“What does that say to Indigenous communities?” she asked. “We’re talking about nation building here, historical mistreatment being righted through ethical protocols.”

Address systemic racism

Bourassa also talked about the role of research in ongoing work by Canada’s Truth and Reconciliation Commission, which over six years heard the stories of thousands of survivors of abuse and neglect at so-called Indian Residential Schools.

This was one of the country’s “darkest chapters”, according to Prime Minister Justin Trudeau.

Bourassa said she did not like to use the word ‘reconciliation’ – “I don’t think that we as Indigenous people have to reconcile anything, to be honest” – but she does believe that research “can provide a path to healing”.

Some common grievances:
- The majority of research projects are initiated, paid for and carried out by non-Aboriginal people from universities government and industry;
- Some researchers have essentially pre-empted meaningful community involvement by presenting completed research designs, often already funded, for community approval rather than collaborating from the start;
- Governments gather administrative and other data on First Nations without their knowledge or consent;
- Governments and researchers analyze, interpret and report First Nations data without consent, approval, review or input by First Nations representatives;
- Research funding is largely controlled by a few external agents and is generally not accessible to community groups and First Nations organizations;
- Human remains and cultural property have been taken for storage, display in museums, or sale (NAHO, 2004).
Among its many comprehensive recommendations, the Commission (using the official term “Aboriginal” for First Nations people, one that Bourassa rejects as a “term placed upon us”) called upon all levels of government to:

- Increase the number of Aboriginal professionals working in the health care field
- Ensure the retention of Aboriginal health care providers in Aboriginal communities
- Provide cultural competency training for all health care professionals.

That requires the government to play its part in reconciliation by helping to increase the number of Indigenous professionals not just in health care but also health research, Bourassa said.

But she also challenged the focus on training in cultural competence.

“If we’re not evaluating it, we have no idea if it’s working. What we really need is to call it out as it is, we have to address systemic racism in Canada.”

“(Health) disparities exist on the basis of race in Canada, full stop,” she said. “Racist oppression and historical legacies perpetuate the state of our health. Racism is actually the biggest social determinant of health in Canada. It’s killing our people.”

In a later interview with Croakey (see below), Bourassa referred to this report – ‘Out of Sight’ – on the death of Brian Sinclair nearly ten years ago and responses to it.

The report was recently released by a group of doctors (led by Dr Barry Lavallee) and several academics to highlight "ongoing structural and systemic anti-Indigenous racism in our contemporary health and legal systems".

It describes in distressing detail how Sinclair went to the hospital to have his catheter changed but was left to wait, and to die.

Health and security staff assumed him to be drunk and/or homeless, despite interventions from members of the public concerned about his wellbeing, including when he was vomiting.

Bourassa said the report has made concrete recommendations about how to address racism in the health system. She will be keeping a close eye on how they are taken up in her region and how other regions react.

“That’s something we could really learn from,” she said.
Watch this video interview

Croakey contributing editor Summer May Finlay interviews Dr Carrie Bourassa about the responsibilities of researchers and research institutions, and the health impacts of racism.

You can also hear more in this podcast interview recorded soon after Bourassa took up her position.

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Stop “ stacking your CVS” and ensure Indigenous communities lead research

#ResearchTranslation17
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South Beach in Brisbane Australia 😊
A “masterclass” in Indigenous health research translation – from Sir Mason Durie

Marie McInerney writes:

Health researchers who want to make a difference for Indigenous people must work at the interface of two knowledge systems – the Western biomedical/bioscience approach and Indigenous knowledge, according to a leading Maori researcher and health specialist.

Sir Mason Durie, one of Aotearoa New Zealand’s most highly respected health leaders, said that health systems and research also had to engage not only with education, housing and other sectors, but be part of legal, historic, land, demographic, economic and language research.

He said researchers must be driven by delivering solutions to communities, not defining their problems.

“They know what went wrong, what they want to know is how to get on a pathway that leads to flourishing community and flourishing families,” he told the 6th National Health and Medical Research Council (NHMRC) symposium on research translation.

Durie, a psychiatrist who was Deputy Vice-Chancellor and Professor of Māori Research and Development at Massey University in New Zealand until his retirement in 2012, delivered what one delegate described as “an impressive masterclass” to the symposium on Indigenous health translation, co-hosted with the Lowitja Institute.
His keynote address outlined Māori experience in translating health research into health gains, which he said had been shaped by four themes:

- Māori research capability building
- Dual accountabilities for the generation, transfer, and impact of new knowledge
- Community priorities and leadership
- Contributions that health can make to wider social, cultural & economic development.

#ResearchTranslation17 keynotes: Dr Carrie Bourassa, leading Meti researcher from Canada & Aotearoa New Zealand health leader Sir Mason Durie, with @RMokak @LowitjaInstitut

Solutions focus

Acknowledging the many commonalities between Indigenous people, Durie said Māori, like other Indigenous people, “live in two worlds, partly Māori, partly Western”.

“That’s also true of the knowledge we have,” he said. “So there are dual accountabilities that researchers have for the generation of new knowledge, for the transfer of new knowledge, and for realising impact from new knowledge.”

Researchers have two obligations if they are to make a difference to Māori people and thus more broadly for Indigenous people, he told delegates.

“There is an obligation to be part of a biomedical, bioscience approach, but also to be expert enough to know what underpins Māori knowledge.

“These are two bodies of knowledge which are different – you can’t explain one by using the arguments of the other.”

Durie defined Indigenous knowledge as generally tending to understand people “not by what goes on inside them but by how they relate to outside them”.

Biomedical knowledge, by contrast he said, tends to go in the other direction: “You understand things by analysing them, breaking them down into small bits, so you can work out what the DNA problem is.”

“Researchers who are going to make a difference to Māori need to be somewhere in the middle of that… to be conversant with both.”
Durie said that much research in the past had been very good at finding out “why things went wrong” but has paid less attention to what went right.

“The solution focus is really what communities are looking for,” he said.

“What’s come through at this conference is that people are not defining themselves by deficits and disparities but by the progress they’ve made, by the potential they have and by the promise of their own work,” he later told Croakey (see the video interview below).

**Key case studies**

In his wide-ranging plenary address, Durie outlined a number of case studies that he has been involved in over many decades to illustrate research impact.

Their key themes, he said, were that they:

- Involved Māori research initiatives, Māori researchers, frameworks and language
- Were aligned with community and tribal priorities, and
- Translated into valuable action.

One of the most recent examples was Te Reo Hāpai – “The Language of Enrichment”, a project to update and create Māori language used in the mental health, addiction and disability sectors and published this year as a language glossary for Māori services across New Zealand.

It emerged, he said, out of concern that many of the terms used in mental health services and diagnostic categories “are often confusing, are often misleading, sometimes unintelligible, and often degrading”.

The new lexicon includes over 200 Māori words, terms and proverbs developed over two years of consultation with people with lived experience of mental health, addictions and disability issues, as well as with practitioners, clinicians and not for profit services.

They include:

- Autism: ‘takiwātanga’ – ‘his or her own time and space’
- Disability: ‘whaikaha’ – ‘to have strength, to have ability, otherly abled, enabled’
- Patient: ‘tāngata whai ora’ – ‘a person who is pursuing health’.
Durie said Te Reo Hāpai is important for the way it uses Māori words – illustrating the capacity of one language to unlock complex descriptions used in another to better convey meaning and understanding – but also because it uses terms that don’t devalue people.

He says in the preface of the publication that it will increase knowledge and appreciation of mental health especially for those for whom Māori is a preferred language, and greatly increase understanding of mental health conditions, symptoms and consequences and in the process will lead to better engagement between whānau (family) and health services.

He writes:

| This vocabulary is especially welcome because it translates words that might carry stigma and discrimination into words that recognise humanity, hope and personal dignity. |
| Patients and ‘service users’ become people again – tāngata whai ora; people with disabilities become tāngata whaikaha with an emphasis on gaining strength and ability; the somatic effects of anxiety such as palpitations – often the most worrying symptoms – are recognised in the word manawapā. |
| In effect the language of mental health becomes more aligned to the people most concerned rather than to those who provide treatment and care.” |

**Shifting from blanket prescriptions**

He also described the Whānau Ora (well families) project, which arose out of concern that service delivery to Māori whanau (families) was “fragmented, poorly coordinated, provider oriented, and short sighted”, with most offering crisis resolution and nothing beyond.

Durie sketched the reality for families needing support:

| You might have the truancy officer, diabetes nurse, corrections officer and the housing people all parking their cars up the (one) driveway, not talking to each other and missing the main point. |
| “There was very little coordination between sectors, very little coordination between services, confusion for families and very fragmented approaches to family development.” |

The project, which had a strong research component, has led to Whānau Ora, which describes itself as “a revolutionary public sector initiative” that devolves the delivery of services to community-based commissioning agencies.

It has a dedicated Cabinet Minister and the heads of three key government departments – Health, Social Welfare and Māori Affairs – sit on its governance board (alongside Māori community representatives), with Housing and Education considering still whether to join.

Services have come together, forming 35 collectives instead of 225 individual services.
Durie said there was still much to be done to integrate sectors and government departments – “no Minister likes to share their boat with others” – but he highlighted how outcomes were assessed based on individual plans that each whaunau (family) was encouraged to make, whether it be to get a child back into school or to settle land issues.

He said:

- **So the results are not measured on how many people (services) were involved but the gains made by the family.**

- **Critical to this are the whanau navigators, who can broker, mediate, be champions for whanau but all the time transferring their skills to whaunu members to provide their own leadership.**

- **That gives much more flexibility and greater ability to focus on the needs of a particular community, a particular family than having a blanket prescription that covers everyone.”**

Another case study detailed the development of the Hua Oranga tool to measure better Māori mental health service outcomes, amid concern that early measurements were capturing “the absence of symptoms” rather than any real notion of wellbeing.

**Overcoming resistance**

Following his address, a delegate asked for advice on how to overcome resistance in Australian governments to incorporating Indigenous ways and knowledge.

Durie said Māori people had been fortunate to have strong champions in Parliament and all eyes were now on the seven Māori Ministers – a record number – who are part of the new Labour Government.

It also helps, he said, “if you’ve got voting power”. Māori make up 15 percent of the New Zealand population, and the population is young, so that power will only increase.

And the power of protest was also important, he said, recalling the leadership of Dame Whina Cooper, founding president of the Māori Women’s Welfare League, who “scared every politician she met”.

As an 80-year-old, she led the famous 1975 land march from far north New Zealand to Wellington, protesting further losses of Māori land.

**Look beyond the health sector**

A final message was that health services and research have to be integrated, within themselves – primary, secondary, and mental health – and with broader sectors and interests.

Most of the health issues that people face don’t depend on the health system, but on a whole range of interventions and policies, he said.

For Māori people, health is part of a wider socio-economic, environmental, and cultural advancement agenda, so a health research team might need to work alongside other Māori research teams or be part of another project involving:

- Māori land research
- Māori historical research
“Health has got to be part of an intersectoral research program rather than expecting that health research by itself can fix the problem or develop pathways to success,” he said.

“The impacts of Māori health research have got to be felt beyond the health sector.”
Watch these interviews

Summer May Finlay speaks with Sir Mason Durie at #ResearchTranslation17

Summer May Finlay speaks with Haze White from Te Whanau O Waipareira about doing translation research on the ground in Aotearoa New Zealand

Also watch this presentation by Sir Mason Durie on Indigenous human flourishing.

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Helpful spiritual partnership bw @nhmrc and @LowitjaInstitut which has benefited this #ResearchTranslation17 conference Sir Mason Durie

You can track Croakey’s coverage of the conference here.
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I thank Sir Mason Durie for an impressive masterclass in #ResearchTranslation17. Thanks @LowitjaInstitut organising committee

Donna TeWhiu @DTeWhiu

Last words of advice & wisdom from Pou Tā Mason Durie 4 Wai-Researcher Haze White who is getting ready 2 present @ the NHMRC17 symposium

A “masterclass” in Indigenous health research translation – from Sir Mason Durie

#ResearchTranslation17

Croakey
“Conference News Service”
New research highlights importance of addressing the needs of Indigenous adolescents

“Huge opportunities” to improve Indigenous adolescent health: image from National Aboriginal and Torres Strait Islander Health Plan

Marie McInerney reports:

The health and wellbeing of Aboriginal and Torres Strait Islander adolescents is lagging behind that of their non-Indigenous peers because their needs differ substantially and are often not identified in policy approaches or met by health and social services.

That’s the verdict from a new study that calls for a broader and integrated view of adolescent health for Indigenous adolescents who encounter a triple burden of health problems – communicable/reproductive/nutritional disease, non-communicable diseases, and injury – that “profoundly differ” from non-Indigenous adolescents in Australia.

“Health needs extend beyond sexually transmitted infection, mental health, suicide and substance use (typically the focus of Indigenous adolescent health programming),” the authors said in an accompanying statement.

The study – Health and wellbeing of Indigenous adolescents in Australia: a systematic synthesis of population data – points to a “huge opportunity”, not only to improve individual and community wellbeing but to help address health inequities.
New research highlights importance of addressing the needs of Indigenous adolescents

Led by researchers from the South Australian Health and Medical Research Institute (SAHMRI) and the University of Melbourne, the study gathered national survey, hospital and mortality data on young Aboriginal and Torres Strait Islander people aged 10-24 years.

The authors say it is the first such profile of Indigenous adolescent health in any country and identifies health needs that have not previously captured attention from researchers or policy approaches. The study has a strong focus on the impact of the social disadvantage.

“There has been a lot of good work in addressing specific areas of Indigenous adolescent health – but this is the first study to take a step back and consider what are the most pressing needs for Indigenous adolescents in Australia to ensure their health and wellbeing,” lead author Dr Peter Azzopardi said.

“This study identified many areas where investments will not only bring improved outcomes for Indigenous adolescents, but also the broader Indigenous population.”

Timely warnings

The study was published recently in The Lancet and launched by Azzopardi, a paediatrician and researcher based at the Burnett Institute, and Professor Alex Brown, head of SAHMRI’s Aboriginal Research Unit at the 6th National Health and Medical Research Council research translation symposium, co-hosted with the Lowitja Institute.

It’s particularly timely, coming as the Council of Australian Governments (COAG) works to “refresh” Close the Gap targets and with the recent release of the findings of the Royal Commission into the Protection and Detention of Children in the Northern Territory.

The authors warn that Australia will not address Indigenous health inequalities without a specific focus on adolescents, who make up one-third of the Aboriginal and Torres Strait Islander population.

They also warn about the health impacts of systemic racism and discrimination, including where that leads to high arrest and incarceration rates.

“Incarceration of young people at this key development stage will have devastating immediate, lifelong and intergenerational consequences; there is a need to invest in alternatives,” they said.

Key findings

Some of the main findings include:

• Mortality for Indigenous adolescents was more than twice that of non-Indigenous adolescents, with about 60 percent of deaths due to intentional self-harm and road traffic injury. Of note, 80 percent of deaths were considered avoidable in the current health system

• Indigenous adolescents were about 40 times as likely as non-Indigenous adolescents to die from rheumatic heart disease

• Rates of acute rheumatic heart disease, pneumococcal infection, gonorrhoea, and type 2 diabetes resulting in admission to hospital were ten times higher than for non-Indigenous adolescents

• By contrast, eating disorders, skin cancers, and anaphylaxis were each significantly less likely to affect Indigenous adolescents
Indigenous adolescents experience an excess burden of mental disorders and substance use, with almost a third of Indigenous adolescents aged 18-24 years reporting high levels of psychological distress, twice the non-Indigenous rate.

Risks for future ill-health were common, with high rates of smoking, and emerging type 2 diabetes and ischaemic heart disease (conditions more typical of adulthood).

Overall, the study found that, for Indigenous Australians, communicable diseases typical of childhood too often extend into adolescence, while non-communicable diseases more typical of later adulthood have too often already emerged in adolescence.

It found that high rates of vaccine preventable disease and a large burden of potentially preventable mortality “suggest that the current health system is poorly responsive” to their needs and that socio-cultural factors play a huge role.

For example, it said, pneumonia was an important contributor to morbidity, which might in part arise from high incidence of influenza, yet Australia’s vaccine schedule does not currently identify Indigenous people aged 5-15 as a high-risk group.

High rates of sexually transmitted infections, including in the 10-14 year age group, that the report said should be interpreted in the context of early sexual debut and endemic infection in the broader community, were also a concern.

These findings, coupled with high rates of adolescent pregnancy and obstetric complications, highlighted the need to redouble efforts around sexual and reproductive health, the authors said.

**Discrimination and disadvantage**

The study tells the story behind the statistics, finding that widespread disadvantage across social and cultural determinants underpins the complex needs identified.

“Experience of racism was common. Many lived in over-crowded homes of insecure tenure and with substandard facilities. Almost 30 percent reported economic stress and food insecurity. One in five reported having been arrested in the preceding five years, one in ten males aged 20-24 incarcerated.”

Azzopardi, who has worked as an adolescent physician in Aboriginal communities and undertook the study as part of his PhD, said he believes the big focus on the social and cultural determinants of health “is a particular strength of this study”.

This was driven, he said, by a national advisory group of six Indigenous young people, three Indigenous adult community members, three researchers, three policy makers and two service providers who “really pushed for us to look at that in detail”.

The advisory group provided input about the reporting framework, interpretation of findings and policy recommendations.

“Other studies which describe population health needs tend to look at disease, injury, and some risk factors but fall short of looking at some of the determinants so it’s really difficult to place those findings in context or really to frame up appropriate responses,” Azzopardi said.

“The advisory group brought a completely new level of inquiry, it really changed the scope of the project,” he said.
Moving from the policy margins

The authors say that the absence to date of a comprehensive national health profile like this for Indigenous adolescents has been “a barrier to effective policy” with the focus on adolescents “largely on the margins of Indigenous health policy”.

“Despite Australia’s adolescents having one of the best health profiles globally, Indigenous adolescents have largely been left behind,” they said.

“Adequate responses will require intersectoral actions, including a health system responsive to the needs of Indigenous adolescents.”

Below is a range of recommendations from the authors on priority approaches:

Engage and empower youth and their communities

Young people are powerful agents of change and must be engaged in the design, implementation and evaluation of research, policy and programs related their health. Communities and families also play a key role in enabling and supporting adolescent health and wellbeing and they should also be respectfully engaged and consulted.

Better match health policy and action to the needs of Indigenous adolescents

The focus of policy needs to reflect the very different health needs of this population. Indigenous adolescents encounter a triple burden of health problems (communicable/ reproductive / nutritional disease; non-communicable diseases; and injury) that profoundly differ from non-Indigenous adolescents in Australia. Health needs extend beyond sexually transmitted infection, mental health, suicide and substance use (typically the focus of Indigenous adolescent health programming).

There is a need to take a much broader and integrated view of adolescent health which includes (but is not limited to): suicide and also non-fatal self-harm, unintentional injury and assault; adolescent sexual health and also reproductive health; mental health which addresses both immediate burden of mental disorder and also supports wellbeing; and key risks for future poor health which include overweight, nutrition, physical activity and substance use.

Ensure health care is accessible, and address health & wellbeing through other sectors

Health systems need to be adapted to respond to the needs of Indigenous adolescents, which consider culture, geography, family and community resources. However, many of the health needs of adolescents such as injury and violence are best addressed through sectors other than health. Inter-sectoral action must include the education sector given schools can be health promoting environments, and education is such as powerful determinant of health.

Ensure accountability of any investment

We need better systems for accountability including better coordination of data systems, greater engagement of Indigenous youth and their families and communities. While data around Indigenous adolescent health are improving, there is a need for further research, particularly to evaluate interventions. There is also a need for a set of indicators to monitor progress against any investments made.
New research highlights the importance of addressing the needs of Indigenous adolescents. #ResearchTranslation17

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

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Health and wellbeing of Indigenous adolescents in Australia: a systematic synthesis of population data

Dr Peter S Azopardi, PhD[2], Prof Susan M Sawyer, MD, Prof John B Carlin, PhD, Prof Louisa Degenhardt, PhD, Prof Nigel Brown, MPH[1,4], Prof Alex D Brown, PhD[2], Prof George C Patton, MD[2]

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Health and wellbeing of Indigenous adolescents in Australia: a systematic synthesis of population data

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When the (non-Indigenous) doctor didn’t know best: researching Indigenous health priorities

The Inala Community Jury: ensuring research is ethically sound, culturally appropriate and locally supported.

**WARNING: Aboriginal and Torres Strait Islander readers are warned that this article contains images of deceased persons**

The second series of Struggle Street on SBS is again raising concerns about whether it transforms viewers’ perspectives about poverty and disadvantage or is “poverty porn” and feeds into more stigma.

One episode was focused on the south-western Brisbane suburb of Inala, raising concerns about the “chronicling of Indigenous despair” for Dr Chelsea Bond, a Munanjahl and South Sea Islander woman, a Senior Lecturer with the Aboriginal and Torres Strait Islander Studies Unit at the University of Queensland, and local resident.

She wrote: “Each time we open up our wounds for public consumption, even when those wounds are not self-inflicted, they are seen as evidence of our incapabilities.”

The strengths of the community in the face of structural discrimination and racism are clearly evident in Marie McInerney’s report below from the recent National Health and Medical Research Council symposium on research translation, co-hosted by the Lowitja Institute in Brisbane.
Inala GP Dr Geoff Spurling, a non-Indigenous doctor and researcher, explains why he believes that funding bodies and policy makers should prioritise funding and support for Aboriginal and Torres Strait Islander researchers.

Marie McInerney writes:

The failings of the adage ‘doctor knows best’ really hit home for non-Indigenous GP and researcher Dr Geoff Spurling when he set out to identify health priorities for Aboriginal and Torres Strait Islander people in suburban Brisbane.

Spurling told a recent conference that he should have known better but he had expected a discrete biomedical issue like cardiovascular disease, diabetes, or even dental health to emerge as a single priority from his research at the Inala Indigenous Health Service.

Instead, his consultations with community members in Inala identified much deeper themes about community strength and complex inter-related and intergenerational social, cultural and environmental determinants of health, including racism, trauma and grief.

They also revealed ambivalence about the relevance of annual Aboriginal and Torres Strait Islander health assessments that are designed to identify risk factors, chronic diseases and implement preventive health measures, with one community member commenting:

“"I'm not sure whether it paints a really honest picture of exactly where my health's at. I think that [it] probably can go a bit more in depth."

[Edward]"

It was all a big wakeup call which led Spurling to see his own privilege – as a white, male doctor – as a “learning disability” and to a recommendation in his PhD that funding bodies and policy makers need to give priority to Aboriginal and Torres Strait Islander researchers to conduct and lead health research concerning Indigenous people.

The work has also led to changes in the health assessments that go beyond asking standard health data and look to find out what patients are going through in their lives.

“I was embarrassed or astounded or both, that as a doctor who had been working in this area for eight or nine years, I really failed to predict the health priorities of the community,” he told the symposium.

He later told Croakey:

"It was all about social determinants: it was housing, it was unemployment, it was experiences of grief and loss, social and emotional wellbeing, it was experiences of racism including institutional racism in the community."

"As a PhD student, I really wanted to move onto my next chapter and work out what the 'one thing' was going to be, but it wasn't one thing."

"No matter how hard I tried to pin people down to one thing, which I look back on with a bit of shame, it was this cycle of intergenerational issues that had come down from colonisation and ongoing colonisation.”
That also hit home when one of his community consultants, a local Elder, ran late for a presentation one day because she had been stopped twice on the way by police. Spurling realised in all the years he had been working in the area, he’d never once been pulled over.

Altogether, it reinforced for him the risk that investigator-driven research not conducted in consultation with the community “may waste resources, misinterpret priorities, or worse represent an extension of colonial control causing further trauma”.

“Hearing it in my heart, instead of my head”

Spurling told the conference that the Inala Indigenous Health Service, headed by Wakka Wakka and Kalkadoon doctor and researcher Dr Noel Hayman, had been carrying out annual Aboriginal and Torres Strait Islander health checks since 2004.

It had developed rich computerised data that had the potential to fill gaps, identified in 2010 research led by Professor Sandra Eades, about the health of the 53 percent of Aboriginal and Torres Strait Islander people who live in urban areas.

One of his PhD supervisors – Dr Chelsea Bond, a Munanjahli and South Sea Islander woman and a Senior Lecturer with the Aboriginal and Torres Strait Islander Studies Unit at the University of Queensland, where he also teaches – suggested he ask key Inala community representatives what they thought the priorities should be.

“How radical was that!” he laughed, admitting he had to be “dragged kicking and screaming” into qualitative research.

But he said it turned out to be one of the best things that ever happened to him.

First up, the research required approval from Inala’s Community Jury for Indigenous Health Research, the first research jury to be established in Australia, set up in 2010 to ensure Inala undertakes health research “that is ethically sound, culturally appropriate, and locally supported using a safe, meaningful, equitable and transparent process”.

It was also situated in the transformative paradigm, which assumes that knowledge reflects power and social relationships within society and seeks to improve the social world by privileging oppressed peoples’ voices, rather than silencing or overlooking them.

As important, his meetings with 21 key informants from the local community got him out of the clinic and into homes and local services to which he had been referring patients but had not had the chance to visit in the years he had been working there.

And they gave him the time and opportunity to hear stories, outside of the doctor-patient setting, about people’s lives, the grief they were experiencing, the funerals they were attending, to hear about their lives more in his heart than in his head.

“Oh obviously it’s opened my eyes to the importance of social determinants, which I probably would have known intellectually beforehand but to actually hear it so clearly and confrontingly, it’s changed the direction of my own research,” he said.

He worries that it’s a perspective that gets “trained out” of doctors as they learn the whole biomedical language and become fascinated by their power to be able to treat or cure some illnesses, forgetting about all the other things that can contribute to health.
“That then is problematic because as doctors we have a lot of power politically and so our peak bodies will lobby for more of funding for emergency departments and reducing elective surgery waiting lists and things like that, but that might drown out calls for money to be put into social determinants,” he said.

“Not just the absence of disease”

Spurling told the conference his informants for the project had given authoritative accounts of how social, cultural, and environmental determinants impacted on their lives, which were also consistent with the Aboriginal and Torres Strait Islander definition of health – that is not merely the provision of doctors or absence of disease.

He shared some of the themes and comments that had emerged:

- Strength of the Inala community, family support, and problems of negative suburb discourse

  “There was something strong about the community that I think was a protective factor.”  
  [Olivia]

  “We weren’t rich, we weren’t really wealthy, we were average . . . but I had that support from my family as well . . . that’s why we graduated.”  [Grace]

- A “cycle” of interrelated, inter-generational, social, cultural, and environmental determinants of health.

  “You give a man a job, he can afford housing, he will no doubt want to look after himself, and he then changes himself as a role model for his children. The health in that is massive. Massive.”  [Lily]

  “I’ve been pulled over [by police] and spoken to like I’m nothing, I think that impacts especially on young people.”  [Noah]

Institutional racism came up a lot, around interactions with Centrelink, housing providers, the Department of Child Safety and police.

And Spurling felt shame when he realised the impact when people joked about or stigmatised suburbs like Inala, which had a lower socio economic profile. He didn’t think he’d necessarily made those sorts of comments himself, but felt he hadn’t called them out enough.

In such an environment of racism and stigma, many of Spurling’s informants were worried about the mental health issues that went undiagnosed in the community and what risks that meant, particularly for young people whose future job or education prospects were bleak.

“If I had to put one at the top of the list, it would have to be mental health because it’s really a silent killer,” said one.

“Talking almost a different language”

As a result of the research, Inala has introduced additional questions in its health assessments, known as the “negative life event scale”.

It now asks a number of questions about people’s experiences of unemployment, crowding in their house, experiences of racism and grief, relationship breakups, gambling, and so on, as well as about community activity, education and other possible protective factors.
Spurling says he benefited enormously through the research from having a good supervising team, including Bond. “She’s got enormous cultural knowledge and really fantastic research skills and that combination was just invaluable in an advisor,” he said.

However, he says he still struggles to “escape” his identity and relative privilege, which he regards as presenting a “deep-seated impairment” to his practice and research.

“I talk about this in the PhD… as a learning disability, so for a long time I was talking to my patients but it was like we were talking past each other, almost with a different language.”

Spurling writes in his PhD:

> **While there may be a role for self-reflexive non-Indigenous researchers interested in Aboriginal and Torres Strait Islander health research, it is Aboriginal and Torres Strait Islander researchers, doctors, nurses, and health workers who are likely to best understand the health stories, needs and priorities of Aboriginal and Torres Strait Islander communities.**

Therefore, he recommends, funding bodies and policy makers need to give priority to Aboriginal and Torres Strait Islander researchers seeking the resources, training, and funding to conduct and lead that work.

**Watch this video interview**

- Read Spurling’s PhD thesis, *Computerised Aboriginal and Torres Strait Islander health assessments in primary health care research*
Watch these video interviews on translating Indigenous health research

At #ResearchTranslation17: from left, Anne Kelso, Sir Mason Durie, Professor Sandra Eades, Dr Carrie Bourassa, Romlie Mokak

Watch this compilation of interviews with keynote speakers, presenters, delegates and organisers by Croakey contributing editor Summer May Finlay.

Dr Carrie Bourassa

Dr Carrie Bourassa, who is Métis and belongs to the Riel Métis Council of Regina Inc, is the Scientific Director of the Institute of Aboriginal Peoples’ Health, one of 13 organisations that make up the Canadian Institutes of Health Research (CIHR).
You can track Croakey's coverage of the conference [here](#).

She talks with Finlay about two of the strong messages to come from her keynote address: for researchers to work properly with Indigenous communities and not just “stack your CVs”; and the role of racism as a determinant of health. “It’s killing Indigenous people,” she said.

Read [Croakey's story](#) about her presentation.

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**Sir Mason Durie**

Sir Mason Durie, one of Aotearoa New Zealand’s most highly respected health leaders, talks about Māori experience in translating health research into health gains, including the critical importance for researchers to operate at the interface of Indigenous and Western biomedical knowledges.

Read [Croakey's story](#) from his presentation.

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**Courageous conversations**

Finlay talks to leading researchers, Dr Chelsea Bond, Dr Ray Lovett and Professor Alex Brown about the difficult conversations that Aboriginal and Torres Strait Islander researchers often need to have with and within their institutions, with other researchers and, at times, their own communities.
You can track Croakey’s coverage of the conference [here](#).

Watch these video interviews on translating Indigenous health research #ResearchTranslation17

Keynote presenters Donna Ah Chee, Central Australian Aboriginal Congress CEO, and John Paterson, Aboriginal Medical Services Alliance Northern Territory (AMSANT) executive director, discuss why health researchers need to support the Uluru Statement from the Heart, the need for ongoing funding for the Lowitja Institute, and how the findings of the Northern Territory Royal Commission into the abuse of children in detention must not just gather dust on the bookshelves, like so many before it.

See also the Croakey story.

Dr Anne Kelso

National Health & Medical Research Council CEO Dr Anne Kelso says the most important message to emerge for her from the symposium is the “centrality of community engagement”.

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Watch these video interviews on translating Indigenous health research

#ResearchTranslation17

Croakey "Conference News Service"
Dr Kelvin Kong

Dr Kelvin Kong, who hails from the Worimi people of Port Stephens, north of Newcastle, qualified as the first Aboriginal Fellow of the Royal Australasian College of Surgeons (RACS), specialising in Otolaryngology, Head and Neck Surgery.

He talks about the need for more Aboriginal and Torres Strait Islander researchers and how better translation of Indigenous health research will deliver benefit for the broader community.

Emma Walke

Emma Walke, Lecturer from the University of Sydney's Centre for Rural Health in Lismore, discusses how her personal stories bring authenticity to Aboriginal health studies and how every health subject should ask as a standard question: how does it affect Indigenous health?
Marlene Longbottom

Marlene Longbottom is a Yuin Bhulung woman who is undertaking a PhD at the University of Newcastle on Aboriginal women’s experiences of interpersonal violence and support mechanisms available in the Shoalhaven region of NSW.

She talks here about the need to recognise existing capacity to put knowledge into action in Aboriginal and Torres Strait Islander communities and to work to enhance it. Her message to non-Indigenous researchers and to research institutions is: “It has to be led by us and if you’re uncomfortable doing that, don’t do that research. If they’re not at the table with you from the start, you’re already assuming a power base and that you know more than the community.”

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Dr Tamara Mackean

Dr Tamara Mackean is a Senior Research Fellow in Indigenous Health at Flinders University and the George Institute for Global Health and was co-chair of the Indigenous-led scientific committee for the symposium. See this preview story.

In this interview she talks about the role of research and policy to ensure health equity.
You can track Croakey’s coverage of the conference here.

Watch these video interviews on translating Indigenous health research #ResearchTranslation17

Haze White

Māori researcher Haze White talks about working at the interface between Western scientific and Indigenous knowledges and finding better ways to report back to communities.

Professor Juli Coffin

Professor Juli Coffin talks to Marie McInerney about the Missing Voices study into communication difficulties for Aboriginal people after stroke and traumatic brain injury.

See also this video interview about the South West Queensland Indigenous Cultural Trail, with Angie Walks and Jane Palmer (see image from website below).
Listen to Indigenous patient experts on how to transform renal care

Dozens of Aboriginal and Torres Strait Islander people with chronic and end stage kidney disease and their carers have issued a comprehensive call to action for health services and federal, state and territory leaders to transform renal service delivery in remote Australia.

Patients and carers from across northern Australia recently shared stories at a special Darwin symposium about the overwhelming loneliness, distress, isolation and financial burden that many Indigenous people experience being treated for chronic kidney disease far from their remote homes and in a complex and often uncaring health system.

Their concerns and solutions are documented in a new report by the Menzies School of Health Research in Darwin: *Indigenous Patient Voices: gathering perspectives, finding solutions for chronic and end stage kidney disease*.

“The main message we want to send to the government is that we want to have our treatment on our own country,” they say.

The event was organised by Dr Jaqui Hughes, who spoke recently at the 6th annual National Health and Medical Research Council symposium on research translation, co-hosted by the Lowitja Institute and focused on Indigenous health.

Her big challenge, she told a panel session on *Courageous Conversations*, is to “be the doctor that your patients need you to be, not the one you necessarily want to be”.

Croakey’s report on the research comes amid news that the Ngurratjuta Aboriginal Corporation has donated an Albert Namatjira painting to an Alice Springs clinic to help it pay nurses to deliver remote dialysis services in the absence of proper government-funded health service provision for communities.

Meanwhile, the Northern Territory News has reported concerns from leading Darwin kidney specialist Dr Paul Lawton, who was also involved in the Indigenous Patient Voices event, about systemic racism in the health system that means Aboriginal people are missing out on kidney transplants. (See tweets at the end of this post).

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Marie McInerney writes:

Eddie Mabo’s daughter Betty Tekahika took her turn to stand and talk, telling the room what it means for Torres Strait Islander people to have to live in Cairns or Townsville for months or years to access dialysis.

“They can’t go back (home), there’s no machine,” she says.

“Their tears are running down their eyes. They want to go back home. They miss their family, they miss the lifestyle of the island, because they’re Islanders.

“They want to go back home. Where’s the government today, looking at the needs of the Indigenous people in the community?”

It was a common lament at this unique symposium in Darwin, led by Dr Jaqui Hughes, Australia’s only Aboriginal and Torres Strait Islander nephrologist, based at the Royal Darwin Hospital, and an NHMRC Early Career Research Fellow at the Menzies School of Health Research.

Held in September, the symposium sought to give a voice to remote Indigenous people being treated for chronic kidney disease and also to challenge the health system’s compliance with and commitment to National Safety and Quality Health Service standards about consumer engagement and the promise of better care for Indigenous patients.

It was organised after Hughes was this year elected to the Council of the Australian and New Zealand Society of Nephrology (ANZSN), “the first time there has been a voice like mine at the national policy level”.

With Darwin selected to host the ANZSN’s 2017 annual scientific meeting, for the first time in 16 years, the local organisers – Hughes, Dr Sandawana William Majoni, and Dr Paul Lawton – wanted to value add, she said.

So, in another first, the ANZSN meeting hosted an all-day patients’ voice session, where 33 “expert-patients and carers” – from regions across northern Australia, from the Kimberley to Thursday Island – sat down in a room with senior clinicians, policy makers and research leaders and shared their stories about living with chronic and end stage kidney disease.

“It was one-way talk,” Hughes said. The “non-patient-carer delegates” were invited to sit and respectfully listen without interruption until the expert patients had had their say, and then, in the final session, just to respond briefly or ask questions.

“The whole rest of the day was patients and their close support people like carers talking about the things that mattered to them, how they experienced care within the health system, about the devastating impact and consequences of kidney illness,” she said.
“We gave them a voice and this is what they came up with,” she said of the report, *Indigenous Patient Voices: gathering perspectives, finding solutions for chronic and end stage kidney disease*, which has major calls to action from governments and health services to address the “huge gaps” in health equity that cause such suffering.

Many of the conversations are also captured in four compelling videos: watch them [here](#).

Hughes has briefed Indigenous Health Minister Ken Wyatt on the recommendations that have emerged from the report, which she says also provides evidence to support a Medicare Benefits Schedule Review recommendation to create a new item number to improve care for regional and remote Australians.

“We hope there will be transformational policy in response to this,” she said.

Minister Wyatt told Croakey:

- *Turning around the tragedy of this disease is one of my top priorities.*
- *Our men suffer kidney health problems at five times the rate of non-indigenous men and the onset of kidney disease is at a much earlier age in indigenous people. The rates of kidney disease steadily increase from 18 years as compared to 55 years for non-indigenous.*
- *I will say much more about this in the coming months, but I am totally committed to working with communities and health practitioners across our nation to reduce the impact of renal failure and, even more importantly, to prevent it happening in the first place.*
- *This means solutions that help people now, but also grassroots strategies that will help ensure our men, women and families continue reaping the benefits in five, 10 and 20 years – for the rest of their lives.*

“It is a sad story and serious problem”

The report opens with patients describing key historic events that have shaped their lives, stories of family being relocated off country to settle in townships, children removed from parents and families, cultural practices and languages, as well as education and employment opportunities, limited or denied.

It says:

- *Patients and careers shared a strongly held belief that repeating the systematic forced removal of people from their homelands, in order to access health care (which has a central delivery focus), has not produced the designed health gains.*
- *They reported the heartbreak of not being able to spend more than a few days away from their dialysis unit … thus never seeing family or country for more than a few days at a time*.

The report quotes many of the patient experts. One says: “We’ve got to leave our homes and come to Darwin. It’s a long way. It is a sad story. Think about it deeply, properly and seriously, because it is a serious problem.”

Patients talk of their loneliness and isolation, exacerbated by limited, restrictive and expensive accommodation options.
They talked about cultural breaches in being on another person’s country without invitation, the difficulty of navigating a very complex health system, of being exposed to racist attitudes, and the deep losses to communities back home who miss their presence in family and culture.

“Sometimes we have to live in the long-grass, because the hostels don’t have enough spaces and we have to move out when they have another booking.”

“Families living in Darwin (for dialysis) are missing out on ceremonies, funerals and other important stuff.”

The report says patients shared concerns across a wide range of areas – from the undermining of homelands (that play important national roles including border security and environmental and cultural heritage protection), particularly with the closure of key regional towns and the loss of critical health services, through to inadequate primary and secondary prevention strategies to inform people at risk of progressive kidney disease.

As well as issues around late diagnosis and poor information sharing, they talked about the vulnerability of being on the receiving end of health services they felt to be uncaring and which punished “non-conforming” patients.

But they also offered specific and holistic solutions, including:

- Better information about the causes, prevention and treatment of kidney disease that takes into account regional difference in culture, language, patterns of kidney health and illness and service provision
- Training and job pathways for Indigenous people in renal care, including personal care for people needing dialysis, health service navigator roles, health promotion, renal-equipped primary health care staff and nursing and nephrologist positions
- Providing renal care close to home so all patients can access home, community and their country and that regions with high needs have fit for purpose dialysis training and support for patients, carers and local staff
- Support from health services for burial on country

Truth telling about systems of care

In the Courageous Conversations panel discussion at the NHMRC and Lowitja Institute symposium, Hughes recommended that delegates watch the 2016 Menzies Oration delivered by Labor frontbencher Linda Burney, on ‘Truth telling and generosity: Healing the heart of a nation’.

“She talked about truth telling and I think that’s where my courage is as a researcher,” Hughes told delegates.

But, she said, the big question for researchers is: whose truth?

That is what the Indigenous Patients Voice symposium and report aim to reflect – the truths of a community that “very clearly wants to be engaged in redesigning the health system to be the way it needs to be for them to succeed as patients living with this devastating chronic disease”.

“Systems are designed for metro places down south and rolled out across the country,” she said.

If Aboriginal and Torres Strait Islander people were ever invited to provide input into tertiary referral centres, that engagement was never sustained, and the results certainly never evaluated. Hughes said:
As a staff member in this industry, I would really appreciate if the system could support me to be the doctor that my patients want me to be.

There’s a huge cultural misalignment from a health care system that provides care to a community with completely different needs and ways of operating.

“It’s a courageous conversation trying to reflect that back into a health service that is not built to have that feedback, not built to operationalise it, that is not flexible.

(As a result), things move slowly…but my patients don’t live that long for slowness to be effective.”

Breakthrough

Hughes also told the NHMRC/Lowitja symposium about a successful intervention in Darwin led by the Royal Darwin Hospital, among dialysis-dependent adults to treat melioidosis, which causes sepsis and death in northern Australia during the monsoonal wet season.

It was an extraordinary research breakthrough, she said, with great potential internationally.

As well as publishing the research around the intervention – which involves giving a 20 cent tablet three times a week after dialysis – the research team has made two short videos to provide a plain language summary for patients and the general community.

• Watch the videos here.

• Follow on Twitter @JHughes
Leading Indigenous health researchers share some courageous conversations

A standout session at the recent 6th annual National Health and Medical Research Council symposium on Indigenous health research translation, co-hosted by the Lowitja Institute, was a panel discussion on Courageous Conversations.

As Dr Megan Williams, Senior Lecturer in Aboriginal Health and Wellbeing at the Graduate School of Health at the University of Technology Sydney and a Croakey contributing editor, said:

“It provided a rare window to the leadership of Aboriginal people in ethical research featuring community engagement – which governments are increasingly calling for – as well as the challenges to stimulate other researchers to conduct their work properly.”

The discussion also revealed the added layers of personal and professional pressures for Aboriginal and Torres Strait Islander researchers, academics and clinicians, including having to deal with racial stereotypes and slurs and systems that cause harm for their communities.

The panel featured Dr Jaquelyne Hughes, Dr Ray Lovett, Professor Alex Brown, Dr Chelsea Bond and Dr Cass Hunter. In a wide-ranging discussion, they talked about the added and often unsafe burdens in their work that include:

• Being expected to speak on behalf of all Indigenous people
• Having to deliver worst case scenarios to individual patients and front-line communities
• Being regarded as suspect because of your deep links to community, and
• Having to worry about white people’s emotional comfort when it comes to conversations about race and racism.
You can track Croakey’s coverage of the conference here.

In the story below, Marie McInerney reports on the discussion and you can also watch this interview by Croakey contributing editor Summer May Finlay with three of the panelists, Professor Alex Brown, Dr Ray Lovett and Dr Chelsea Bond.

See also the full one-hour panel discussion on leadership, chaired by Associate Professor Gregory Phillips here (with some tweet reports at the end of this post, together with the Twitter analytics).

Marie McInerney reports:

The need to “centre white people’s feelings” in conversations about race is holding back efforts urgently needed to address the impact of racism upon Aboriginal and Torres Strait Islander people, according to leading Indigenous academic and researcher Dr Chelsea Bond.

Bond is an Aboriginal (Munanjahli) and South Sea Islander Australian and a Senior Lecturer with the Aboriginal and Torres Strait Islander Studies Unit at the University of Queensland.

She was recently awarded an Australia Research Council (ARC) Discovery Early Career Researcher Award (DECRA) to advance understanding of the importance of race in contemporary Indigenous public health discourse and practice.

She told the panel discussion there is a long tradition in Australia of “black people having to service white people – economically, physically, emotionally in all kinds of ways”.

So, she said, when it comes to conversations about race, there is an expectation that black people will continue to service white people’s needs, in ways that would never happen in other debates about equity or oppression.

She drew two comparisons:

- **As a woman, if I was to talk about gender equity, it would be absurd to suggest I should (do so) in a way that makes men feel safe.**

- **If I was to talk about class as a power structure, it would be ridiculous to suggest the poorest talked about poverty in a way that makes wealthy people feel good about their circumstance.**

- **We wouldn’t do that but when it comes to race, we insist that blackfellas talk about it in a way that makes white people feel really comfortable.**

- **I think that requirement… maintains the power of race and the production of racial inequities.**

Bond lamented a “lack of critical race scholarship” in Australia, which is hindering the country’s ability to engage intellectually on race and racism, and where culture “tends to be the default and the decoy away from talking about race”.

“We need to read, we need to learn, we need to teach about race, not just have it as something we talk about in the hallway,” she said. “It’s an important field of scholarly inquiry.”
Bond also urged other Aboriginal and Torres Strait Islander people working in Indigenous health and health research not to disparage their specialist knowledge about race, saying that growing up with a black father and a white mother had given her deep insights. She said:

I know how race works, I saw it every day... Many of us who know how it works have been told to ignore it, dismiss it, downplay it, be ten times better, outperform, overcome it.

No.

We need to study it, understand how it works so we can undermine it.”

Inspired by Professor Lester–Irabinna Rigney’s Indigenist research framework, Bond also urged Indigenous health professionals to “embrace the notion of non-compliance, both clinically and politically” and to have “disciplinary deviance in our work”.

In a brutal system, in health as well as justice systems, it should not be seen as courageous for health researchers to call out harm and the imperative to act.

“Our communities are waiting for us to do better, our people are dying,” she said.

Asked for solutions to conversations about race that don’t centre white people’s feelings, Bond offered three steps:

1. Stop saying ‘the R word’ as if it is on a par with ‘the N word. “It’s not, it’s different. We have to name race and racism,” she said.
2. Emphasise and foster intellectual engagement with race conversations, not people’s emotional responses to race conversations.
3. Focus on the outcomes for Indigenous health, not aspirations or intentions.

“Sick to death of the sickness and death”

Professor Alex Brown told the conference there are a few key questions that invariably and frequently herald difficult conversations for him as an Aboriginal person, doctor and public health researcher.

They include: “How Aboriginal are you?”, “Who do you think you are?” and – from patients – “Will I live to see my children start school?”

All are signposts to difficult, often hurtful and insulting conversations about race, identity, and authenticity, or to manifestations of discrimination and disadvantage that are an added and very personal burden for Aboriginal and Torres Strait Islander researchers, he said.

Head of the Aboriginal Research Unit at the South Australian Health and Medical Research Institute (SAHMRI), Brown talked about the emotional toll of being both a clinician and fellow community member to patients with a poor prognosis and as a researcher investigating the disproportionate burden of disease borne by Indigenous people.

“It’s not hard to get sick to death of all the sickness and death we record because we are the scribes of that reality, and we’ve got skin in the game, it’s our family, it’s each other, it’s the people we worked with last week,” he said.

Another big struggle, he said, is being on the front-line to try to improve health outcomes for Aboriginal and Torres Strait Islander people but with little power to make that happen. He said:
We work really hard at translating our work, there’s no doubt that it’s a central requirement to everything we do.... but the challenge is that most of the levers for change are outside our control.

They’re in departments, in funding mechanisms, outside our ability as Aboriginal people, organisations and community to change.

We’re expected to solve the riddle of the sphinx with nothing to solve it with, beyond our brains and hearts and spirits and our connection.”

And then there are the everyday racial slurs that are both personal and professional.

They come from colleagues or others in the clinical environment, after he’s observed poor treatment of Aboriginal people in the health care system.

In such cases he will often end up saying, “you know I’m Aboriginal, right?”, to be met with, “how Aboriginal are you?”, and then, “well, you’re not like them”.

He said: “The reality is I am really like them, because they are me, we are us, and to deal with, obviously as a very light skinned (Aboriginal person), obviously my own issues of identity notwithstanding...it’s a challenge, we get asked these questions all the time, these are difficult conversations to have and I’ve really struggled with them.”

Another frequent question – “who do you think you are?” – can be posed aggressively or with kindness, but more often than not is “hard and difficult and painful”, particularly when it comes from other Indigenous people.

“I don’t mind hearing that from non-Indigenous people in our field – we hear it a lot – but it really hurts when we hear it from our mob and that’s probably the difficult stuff we don’t talk about enough, (about) how willing we are at times, because of the pain and suffering we’ve endured ourselves, to bring down people around us, rather than build each other up.”

**Damaging expectations**

Australian National University researcher Dr Ray Lovett talked about his experience of being “the only Aboriginal person” in a research unit, constantly expected to be the font of all Indigenous wisdom, whether on welcome to country protocols through to how best to engage with a community.

“I speak for me, I don’t speak for everyone,” said Lovett, a Wongaibon/Ngiyampaa man from New South Wales who is the Program Leader for Aboriginal and Torres Strait Islander Health at the National Centre for Epidemiology and Population Health at the ANU.

But he said that to tell that to colleagues or the institution and to suggest instead how they should go about speaking to the right Indigenous person or community on the particular issue they want help with “leads to decision paralysis”.

Brown agreed, saying later in an interview with Croakey:

“We’re expected to know everything about everything Aboriginal, expected to speak on behalf of everyone, expected to know all of the policy imperatives, there to solve every Aboriginal problem that the institution or organisation has.... to lead them to Nirvana on all Aboriginal fronts and then try to balance the realities of what our communities and families expect of us as well.”
Lovett told the conference he also faces issues around authenticity, not just within the institution or his discipline, but across to community and even family, particularly around policy work. He said:

Those questions about how authentic I am as an Aboriginal person are raised on a daily basis, because I don’t speak the right way in certain contexts or dress the right way…. or people have perceptions about where I’ve come from and how I’ve grown up when they’re meeting me for the first time.

I definitely have a sense sometimes that I don’t fit in the Aboriginal world and definitely at others …that I don’t fit in the academic world.

That’s a really hard space to be in when community members say to you ‘you’re different, you’re more of a whitesella’, or conversely, when the university is a bit suspicious of you because you align yourself very much with community.”

Lovett highlighted the impact too for Indigenous researchers, who understand context and different knowledge systems, amid the fierce competition for funding, rather than collaboration, particularly where greater status is given to quantitative research.

“The paradigm in unis and academia about what is evidence or which evidence is privileged, it’s a huge problem we have to deal with,” he said.

“The numbers sure give us that hit in the face about what’s going on but the qualitative component really contextualises and tells us what that story means.”

Climate conversations

Some of the hardest conversations for Dr Cass Hunter come when she has to talk to communities about the impacts of environmental and climate change.

Hunter is a Kuku Yalanji and Torres Strait Islander woman, working as an Indigenous social ecological research scientist with CSIRO Oceans and Atmosphere, with a focus on the resilience of communities in the Torres Strait.

Because those communities are on the frontline of climate change, there’s a risk that talking about ‘uninhabitable homes’ and ‘displacement’ causes distress and starts to work against their wellbeing and to break down connections to island life, she said.

“As a researcher, I have to be very mindful of that, about that distress, about ‘worst case scenarios”,’ she said. “We’ve got to allow communities to handle conversations around that in their own way.”

It was a message that resonated across the two-day symposium – of making sure that communities are not only fully engaged in, but lead research.

“People are looking for that golden lever to pull down, but it’s a bit of an illusion,” Hunter said. “Often you need to focus on solutions that are empowering, put communities in the driving seat.”

Alex Brown also had some practical advice, “largely for whitesellas in the audience”, including that trust is critical. He said:

One of the reasons Aboriginal and Torres Strait Islander research takes so long is we’re building capital in trust and relationships that take a lot of time to build and a second to screw up.
This is a very difficult balance for us to maintain constantly, that’s why we’ll always defer to looking after our communities rather than institutions.

Communities should be able to have as much time as they need to decide whether your new world saving project is worth their support.”

And all of this shows the need for a research framework to be developed by an organisation like the NHMRC, according to Dr Jaqui Hughes, Australia’s only Aboriginal and Torres Strait Islander nephrologist and an NHMRC Early Career Research Fellow at Menzies School of Health Research in Darwin. (See this article about her work: Listen to Indigenous patient experts to transform renal care).

Hughes told the symposium she was tired of non-Indigenous colleagues “expecting me to go and do that engagement for them”.

She later told Croakey: “We need to create the research framework that supports researchers to go and do community engagement properly, so you can’t say this is a suggestion.”

It needs, she said, to ask: “have you done it, where do you demonstrate that, is it more than a cup of tea or a nod in the street? … what are you delivering back to the community that benefits the community now and not just to you as a researcher or to a research institution.”

Leadership dimensions

The symposium also hosted a panel discussion on leadership, led by Associate Professor Gregory Phillips, that can be viewed in full here.

Among the highlights was a discussion between Professor Gail Garvey, Senior Principal Research Fellow at the Menzies School of Health Research, and her colleague and mentee Dr Lisa Whop, who is a research fellow at Menzies School of Health Research, working on the National Indigenous Cervical Screening Project.

Key points were:

• The importance of trust – not just in each other’s work and research, but intentions: “Trusting that Gail’s intentions are for my own personal growth not for her CV,” Whop said

• Making space – Whop quoted an Oprah Winfrey interview with US basketballer Michael Jordan’s coach who said “a leader has to create a space for other people to step forward and lead”

• Letting go – Garvey said at one stage she had encouraged Whop to follow her dream to work elsewhere (though she was glad she came back) – “I didn’t try to hang on to her… it’s hard to train and develop your staff and let them go, but it’s most important they have a broad depth of experience to have the most impact, and that may or may not be in your team.”
Watch this interview

Leading Indigenous health researchers share some courageous conversations
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Tweet reports

Kelvin Kong @KelvinKongENT · Nov 13
All Aboriginal panel #ResearchTranslation17

Summer May Finlay @OnTopicAus · Nov 13
As do I Staying in the Indigenous box we are subscribed to will only maintain the status quo. A status quo which will not see improvements for our mob.

#researchtranslation17

Michelle Bovill @michelle_bovill
I strive to be disciplinarily deviant too @drcbond #researchtranslation17 @LowitjaInstitut
You can track Croakey's coverage of the conference here.

Leading Indigenous health researchers share some courageous conversations

#ResearchTranslation17
Leading Indigenous health researchers share some courageous conversations

#ResearchTranslation17
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**VAHS HLT @VAHSHLT • Nov 13**

"When I see a change in my people, that supports me going forward." Dimensions of leadership with inspiring Aboriginal leaders. #ResearchTranslation17 #NHMRC #LowitjaInstitute #Lowitja #VAHSHealthylifestyleteam

**Marie Mcinerney @mariemcinerney • Nov 13**

Dr Brett Shannon, ED physician, Institute for Urban Indigenous Health director: “When my partner found out I was talking about self-care, she laughed at me.” #ResearchTranslation17

**chelsea bond @drchbond • Nov 13**

A/Prof Gregory Phillips talking abt intellectual leadership in our time Dr Aunty Mary Graham & Dr Aunty Lila Watson #researchtranslation17
You can track Croakey's coverage of the conference [here](link).

**Lowitja Institute** @LowitjaInstitut · Nov 13

We need to understand what's needed for success for each individual. Wonderful relationship between mentor @ganey_cail and mentee @Lisa_J_Whop also a @LowitjaInstitut past PhD scholarship holder. #ResearchTranslation17

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**NHMRC** @nhmrc · Nov 14

Prof Anne Kelso: This is a lesson for the whole health system. Indigenous health research can lead the way.

And that's a wrap! A huge thank you to our speakers, participants & @LowitjaInstitut for making this such successful conference #ResearchTranslation17
You can track Croakey's coverage of the conference here.

**Twitter impact**

Warm thanks to all #ResearchTranslation17 conference tweeps – you had the event trending nationally, with almost 42 million Twitter impressions, and 1,226 participants.

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<thead>
<tr>
<th>The #researchtranslation17 Influencers</th>
<th>The Numbers</th>
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Tweet Activity on #researchtranslation17

**#researchtranslation17 Participants**

Data for #researchtranslation17 can be up to 15 minutes delayed

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**Marie McInerney @mariemcinerney • Nov 13**

Which Twitter space would you like to be in? I’m saying head for #ResearchTranslation17 - big serious subjects and lots of laughs too 🤖

**#Healthwellbeing - STILL trending nationally without a quitting MP in sight**

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**Australia trends • Change**

- **Senate**
  - 333K Tweets
- **Ben Neelong**
  - Former NSW premier Kristina Keneally will run as Labor candidate for Ben Neelong
- **Jacqui Lambie**
  - Tearful Jacqui Lambie resigns from Senate over dual-citizenship
- **Michelle Guthrie**
  - #SBS2018 @brmbenjaminslaw, @OnTopicAus and 1 more are Tweeting about this
- **#ResearchTranslation17**
  - @Chirgwin and @croakeyblog are Tweeting about this
You can track Croakey's coverage of the conference here.

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#ResearchTranslation17

Croakey Conference News Service

• Reporting by Marie McInerney and Summer May Finlay
• Editing by Melissa Sweet
• Layout and design by Mitchell Ward