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This report was produced by Mitchell Ward and Melissa Sweet to provide Croakey readers with some summer holiday reading. Please read and share ...
# Contents

Introduction ...................................................................................................................................... 1

Today is tomorrow’s history – be brave, so we can envisage Australia in 2037 like this .......... 7

Strong message to Turnbull Government from researchers – support Uluru Statement and Lowitja Institute .................................................................................................................................... 17

The “suburbanisation of disadvantage”: a critical concern for public health and planning sectors ........................................................................................................................................ 20

Some big questions about life and death: challenging “conveyor belt” of Western medicine and wishing for a loving end ........................................................................................................ 25

Courageous Conversations at #ResearchTranslation17 .................................................................. 30

When a mental health unit introduced a peer workforce, what happened next? ......................... 31

Around the world in 79 days: re-writing colonial narratives .......................................................... 36

Calling for a minimum price for tobacco products, and action on retail licensing .................... 47

Ten powerful points for the health sector: lessons from #LBQWHC17 ........................................ 52

Hope and strength as a new generation of Indigenous doctors is welcomed at #AIDAconf2017 ........................................................................................................................................ 61

Tweets from a Doctors for the Environment Australia conference ............................................. 65

Unfinished business: Health & other sectors urged to address unmet needs of Stolen Generations ....................................................................................................................................... 68

The future is fast approaching, but are we ready? A LongRead on what AI might hold for rural health .......................................................................................................................................... 73

Indigenous Data Sovereignty: More than scholarship, it’s a movement ...................................... 78

Why the NDIS was a hot topic at #LivingOurWay – and stacks more conference news ............ 87

Indigenous allied health professionals are leading change ........................................................... 95

Health equity, prevention and better integration of services: key priorities from the ALP Health Summit ........................................................................................................................................ 100
Introduction

**Marie McInerney writes:**

This year, I’ve spent nearly two full weeks in total at seven public health conferences across Australia, live tweeting, broadcasting video interviews and following up over the following days and sometimes weeks with news and feature stories.

As a journalist, to spend two or three full days (and often nights) immersed in a single conference is a gift at a time when mainstream media’s capacity to cover health and social issues in depth and breadth is ever diminishing.

Since its launch in 2013, the Croakey Conference News Service has covered 60 conferences across Australia, on Indigenous health (including global conferences on cancer and HIV and AIDS), rural and remote health, mental health, primary care, medical regulation, obesity, over-servicing, and many other issues.

Each conference has its own compelling stories and spirit, particularly those focused on Indigenous health and wellbeing – as National Health & Medical Research Council CEO Professor Anne Kelso experienced at the 6th Annual NHMRC Symposium on Research Translation, co-hosted with the Lowitja Institute in Brisbane in November (#ResearchTranslation17).

“What a meeting,” she told delegates in her closing speech, saying she had been “absolutely blown away” by the two-day event that opened with powerful Welcome to Country ceremonies and featured “courageous conversations” about race and racism in health and health research systems and workforces.

“It’s the spirit of the meeting that’s been so extraordinary and unlike anything I’ve ever experienced before,” she said. “I think it’s that spirit of sharing, spirit of humility, and spirit of community that we’ve heard so much about.”

**The power of lived experience**

Another standout for me this year was the Victorian Mental Illness Awareness Council (VMIAC) biennial meeting(#VMIACConf17), which created a space filled with laughter and tears as speakers called out the harm and trauma experienced by mental health consumers in health services, workplaces and the community – and also celebrated their strengths, victories and “different (and) … larger ways of being in the world”.

We saw similar themes emerging from the TheMHS conference in Sydney that centred the voices of lived experience, and was covered by Amy Coopes (#TheMHS2017). Delegates heard that employing peer workers in mental health is about much more than ensuring their voices are heard – it is a political act that re-frames the balance of power and is part of a movement towards greater equity, rights and justice.

Conferences can provide a platform for voices still too rarely heard in wider public debates, and it is a privilege to be in the room to hear them, as well as to bring them to Croakey’s readers.

More generally, these conferences, as profiled in this publication, enable us to connect Croakey and our readers to leading thinkers and practitioners in multiple fields and to current research, to the evidence of what works to improve health and wellbeing.
The need to get that evidence out more widely has been highlighted by former Northern Territory Royal Commissioner Margaret White, who despaired at the lack of political will to learn from the overwhelming international evidence on failed youth detention and child protection systems, like Don Dale.

“The evidence from around the world was overwhelming about this system not working; it wasn’t as if it was a very recent phenomenon. It was quite well established, and I find it terribly depressing that those who get elected to high office seem disinterested in evidence-based solutions,” she said.

Others don’t even want to hear the very words, according to news that the Trump administration is prohibiting officials at the US Centers for Disease Control and Prevention from using the following words or phrases in pre-budget documents: “vulnerable,” “entitlement,” “diversity,” “transgender,” “fetus,” “evidence-based” and “science-based.”

**Editorial independence**

As our website explains, the aims of the Croakey Conference News Service include to:

- provide a service to Croakey’s readers by helping to disseminate news from events with public interest merit
- test new models for the funding and production of journalism
- help ensure the sustainability of Croakey.

There are inherent tensions in this funding model – how to ensure editorially independent coverage while being funded by the conference organiser (or, in one case this year, by our own crowdfunded campaign for #HealthMatters).

We seek to manage these tensions by ensuring our reporting is anchored in Croakey’s commitment to transparency and independence.

The service is available only to those conferences or events that we judge to have some public interest merit, and that are likely to be of interest or use to our readers.

While conference organisers pay for the time and costs of journalists and editors, the reporting remains independent, not directed or vetted by organisers.

We stress: this is NOT a media and public relations service, and we find organisers generally respect that as much as we do.

We offered the service as an example of media innovation in our Croakey submission to a Senate inquiry into public interest journalism.

The inquiry offered great promise when it was set up earlier in the year by high profile Senators, including Scott Ludlam, Nick Xenophon, and Sam Dastyari, to look at the structure of media organisations, tax arrangements, competition policy and the increase in fake news – but is worryingly waylaid now by their departures.

**Immersion and social journalism**

The gift of these conferences for Croakey is the immersion and the opportunity to practise what we describe as social or standpoint journalism (you can read more on that in an upcoming edition of Australian Journalism Review).

For me, that includes seeking solutions rather than describing ills, privileging the voices of consumers and communities who too often go unheard, and celebrating a community at work.
Conference presentations on the harms that health and social systems often inflict on individuals and communities also usually have lessons for the media and journalism. I flinched, for example, through a keynote address at the #ResearchTranslation17 conference by Canadian Indigenous researcher Dr Carrie Bourassa, warning about “helicopter” research that is more about “stacking CVs” than public good.

Conference reporting has also offered new and exciting collaborations in journalism. There’s nothing like covering one with Summer May Finlay, a Yorta Yorta woman, academic, public health consultant and contributing editor at Croakey, to see keynote addresses and research presentations through her lenses (not to mention watching her broadcast live on Periscope with one hand while live-tweeting with the other).

But as well as the Croakey Conference News Service being a gift for my journalism, it’s also this year a practical one.

Among my stocking fillers this Christmas are the report of the 14th National Rural Health Conference for my brother, who works in local government, and for my father-in-law, who rails about the lack of attention in Australia for rural issues.

The report of the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives conference is printed and wrapped for my sister-in-law, who works as a nurse in aged care.

**Summer reading - please enjoy**

We are also pleased at Croakey to offer this publication – *Croakey Conference Highlights 2017* – as a gift to our readers. We hope it is a useful and enjoyable addition to your summer reading.

It profiles a story and/or video interview from each conference and event covered this year.

We thank all conference reporters, organisers, presenters and tweeters who engaged with us in 2017 – see the list [here](#).

(And if you are organising a conference in 2018 that is likely to be of interest or use to Croakey readers, please don’t hesitate to ask for a conference reporting proposal…)
Disasters, conflicts and climate change are escalating threats to global health security

As disasters escalate within Australia, our region, and globally, how prepared are our health systems to cope, and what challenges might we face?

These were recurring questions at the annual scientific meeting of the Australasian College for Emergency Medicine (ACEM).

In a meaty program tackling some of the biggest issues for emergency medicine, sessions ranged from climate change-driven disasters and public health emergencies like thunderstorm asthma, through to lessons from the 2014 West Africa Ebola outbreak.

Amy Coopes writes that the targeting of health facilities and staff is another critical challenge for global health security, with the World Health Organization (WHO) documenting almost 1,100 of these attacks over a 3.5 year period.

In the video interview beneath the article below, the WHO’s Dr Rick Brennan also describes the development of new collaborative models to restore health services to countries experiencing protracted conflict, such as Yemen.

Amy Coopes writes:

The World Health Organization (WHO) is facing “unprecedented” demand globally for crisis responses, according to Dr Rick Brennan, an emergency physician from Australia who is director of emergency operations at the WHO.
He said the WHO was currently dealing with nine top-tier incidents – well above the projected trend of one every few years – with four new events emerging this year alone, in Bangladesh, the Democratic Republic of the Congo, Ethiopia and Somalia.

Crises in Syria, Iraq, South Sudan, northern Nigeria and Yemen had been going for some time and were continuing to pose challenges, he said.

The data he presented was staggering: more than 200 new disease outbreaks every year, 200 million people affected by natural or technological disasters and 65 million people displaced globally – 80 percent due to conflict.

He said 1,500 new pathogens had emerged, with major outbreaks in recent years of SARS, H1N1, MERS, Ebola and Zika.

Climate change was already contributing to this picture, Brennan said, giving the example of the Darfur conflict, which was largely driven by drought.

**New approaches needed**

With the conflict in Syria now running longer than World War Two, and the average displacement period for refugees globally at seven years, Brennan said business as usual in the relief and development sector was no longer an option.

The protracted nature of conflicts presented a major challenge in the delivery of health care, with the traditional method of rush in, deliver aid, rush out being outdated and ineffective, and donor fatigue a constant issue, he said.

Because they endured for so long, contemporary conflicts also presented multi-factorial health challenges far beyond simple trauma, with major outbreaks of cholera, lassa fever, malaria and yellow fever in Yemen this year alone.

The modern context also posed unique threats for health workers, Brennan said, with facilities and staff increasingly targeted. Between 2014 and 2017, there had been more than 1,000 such attacks, claiming 1,500 lives.

Funding, lack of local capacity, state fragility and insecurity and bureaucratic bottlenecks were also issues in the delivery of health, he said.

In recognition of the major risk to global health security of protracted conflicts, Brennan said the World Bank had put unprecedented new funding on the table for a pilot in Yemen on a new relief delivery model which, if successful, would be rolled out in other top-tier contexts. This pilot was a partnership with the World Food Programme, WHO and UNICEF.

In a bid to stay ahead of the curve, Brennan outlined the WHO’s global event-based surveillance system, which reviewed about 3,000 signals a month and actioned rapid risk assessment on those deemed to be of significance to public health at a national, regional and international level.

This, and other measures, including a new global health security agenda to replace the old international health regulations, had assumed greater importance following the 2014 West Africa Ebola outbreak.

He said 85 countries had signed onto the new agenda and 47 had tested their national systems, with after-action reviews in 10 countries where outbreaks had occurred.

“Ebola really was a watershed in how we think about global health security,” Brennan told delegates.
The event had exposed “very limited capacity at a country, regional and global level to prevent outbreaks, prepare for them and respond effectively,” he said.

**The “real heroes”**

Brennan described national health workers on the frontlines as the “real heroes of the day”, facing a risk of contracting the deadly haemorrhagic disease 32 times greater than the rest of the population, as well as collapse of local health systems due to the pressure, with implications for malaria and other chronic conditions.

Ultimately, 898 health care workers contracted Ebola during the response and there were 518 deaths: 50 percent of these occurred in nurses and 12 percent among doctors. The vast majority of these were locals, with just 18 cases among international workers and three or four deaths.

Brennan said weak local health systems and a delay by the WHO in recognising and responding to the outbreak had been factors in its spread, with 28,000 cases and 11,500 deaths by the end of the event.

Fear, rumours and misunderstanding among local communities had also contributed to this “perfect storm” of outbreak escalation, he added. Engagement of civil society including religious and women's groups had been essential in addressing this.

**UNMEER**, which Brennan described as the world's first public health emergency response, faced considerable logistical challenges, having to build 72 medical centres, deploy 50 foreign teams and 27 mobile laboratories as well as 280 burial teams.

He said 5,500 WHO staff were trained and 1.42 million pieces of personal protective equipment (PPE) were delivered.

Vehicles, accommodation and other sites posed an infection risk. Medevac with biocontainment capacity and a willing end destination were challenges, and in the end Brennan said no country was willing to accept evacuated African locals, only foreign staff.

“We really were building the ship as we were sailing it,” said Brennan of the Ebola response.

**Watch this interview**

[See here](#) for the rest of our coverage of this event.
“Great speech by Janine Mohamed CEO of CATSINaM on her vision for Indigenous health in 2037 - inspiring for a better future” – David Butt, Chief Executive Officer of the National Rural Health Alliance on Twitter (@DavidButtFive)

Today is tomorrow’s history – be brave, so we can envisage Australia in 2037 like this

It’s 2037 and Janine Mohamed’s grandchildren are learning about the tremendous achievements of Australia’s first Indigenous Prime Minister, Mr Adam Goodes….

Twenty years from now it’s a country that has closed the gap in health outcomes for Aboriginal and Torres Strait Islander people and non-Indigenous Australians, where cultural safety doesn’t begin in the health system but in our homes and schools and public discourse, and where recognition of the urgency of climate change has prompted a profound sea change around the world in the way we live and do business.

It’s no wonder this speech from Mohamed – CEO of the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) – sparked such a big response at the National Rural Health Conference in Cairns.

She imagined a strong, positive future for Australia 20 years from now – and what it might take to get us there.

You can read her speech in full below, or watch it via the video link at the bottom of the post. See below too for some of the Twitter responses to her call for action for us to be brave and to make some great history.

Thanks to Janine Mohamed and CATSINaM for making her speech and slides available for this post.
Janine Mohamed: speech to the National Rural Health Conference

Good morning ladies and gentlemen, Elders, dignitaries and colleagues.

I would like to begin by paying my respects to the Traditional Custodians of this land, the Yirrganydji Gimyayg Yidinji people, and to Elders past and present, and future generations.

Thank you for your very warm welcome and for the invitation to talk to you today.

About two years ago I had the privilege of meeting Professor Moana Jackson, from Aotearoa. He is truly an inspirational Maori leader, who challenged us at CATSINaM to ‘see beyond the mountain’, to vision our future at all costs, and to be brave because that is the way of our people.

He also reminded us that we are storytellers – Moana has inspired me to share our hopes for the future with you today.

So….hang on to your seats – we are going to be doing some time travel together!

Becoming advocates and agents of change

When I was a young girl I realised I wanted to become a nurse, after seeing my family members suffer traumatic experiences at the hands of the health system.

While I have worked in many different roles across the health system – clinically, in program development and delivery, academia and in policy – I am now very pleased to be leading the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives, or CATSINaM, since 2013.

I am proud to be an advocate for the unique and powerful roles that Aboriginal and Torres Strait Islander nurses have in the health system and their communities, as agents of change.

I like to begin my speeches by acknowledging May Yarrowick, who trained as an obstetric nurse in Sydney in 1903. She may well be our first Indigenous nurse qualified in Western nursing.

Let’s take a few moments to reflect upon the challenges that May must have overcome to train and work as a nurse in those times. Remember, this was just a few years after the new federation of Australia passed the Immigration Restriction Act of 1901.

This legislation enshrined the White Australia policy, embedding dominant culture worldviews and priorities into the very birth of the federation, and of course the exclusion of us from Australia’s birth certificate.

Some might say that to this day Australia has not yet grown up, or out of those views.
Too often, the limitations of these dominant culture worldviews stop non-Indigenous people from recognising the incredible strengths of our Aboriginal and Torres Strait Islander peoples and cultures.

**Imagine this is now 2037....**

Now, I’d like to invite you to cast your minds forward.

Imagine that we have travelled forward in time from May Yarrowick and 1903, all the way to 2037 – 20 years in the future from the time of this conference here in beautiful Cairns.

How old are you in 2037?

I am 62. I think I look like I belong on the set of the Golden Girls – the Black Betty White. But I am not yet retired. Now that we all are living longer, the retirement age is now 70.

I am happy to still be working. In fact, I am happy to still be alive and in relatively good health.

When I think back to 2017, I remember that I was not at all sure this would be the case. In my early 40s I developed a chronic disease and worried about what it might mean for my future health. But my worries proved unfounded. As I grew older, I remained strong and well.

When I think back over the last few decades, I realise that what helped to keep me feeling good was the strength of my identity, my connection to community and country, and my mentors.

The health literacy that I developed through my nursing career also helped – just one of many ways that developing an Aboriginal and Torres Strait Islander health workforce helps to improve the health of our people.

At 62, I must admit that I am feeling pretty good about myself. My life has had – and continues to have – purpose and meaning, thanks to my passion for improving the health of my people.
So much of my work has been about re-writing national narratives that were once so detrimental to our well-being but are now a source of pride and strength in our identities as members of the world’s oldest living cultures.

One of the reasons I’m so happy is that I am now watching my grandchildren thrive.

I am seeing that their experiences at school and university are so different from my days and even from those of my children – their parents.

My grandchildren are reading histories and textbooks that have been written by Aboriginal and Torres Strait Islander people.

My grannies are learning from Indigenous teachers and lecturers and television presenters. And they are proud and strong in their identities because of how and what they are learning.

It is such a far cry from when I was at school and university. Then our romanticised and exotic histories were being told by non-Indigenous people, who too often saw us through the overlapping lenses of deficit, unconscious bias and racism.

My grandchildren are learning about the tremendous achievements of our first Indigenous Prime Minister, Mr Adam Goodes.

From their classrooms, they scan in to hear the discussions from the First Nations Parliament.

Self-determination is not an aspiration or even a dream for my great grandchildren. It is their daily reality.

They grow up conscious of whose country they are on

In school, they learn about our many Indigenous health heroes — about people like Professor Tom Calma, Aunty Pat Anderson and Aunty Gracelyn Smallwood…….

It is not only my grandchildren who are learning about the strengths and proud history of Aboriginal and Torres Strait Islander peoples – so are their non-Indigenous classmates. Together, they are learning a shared, true history of this place we call Australia.

My grandchildren and their non-Indigenous friends share in learning local language and they learn together about the importance of respecting and caring for country. They grow up knowing about whose country they were born on – because this is written on their birth certificates and is part of their identities from the day they are born.
They grow up knowing to always be conscious of whose country they are on – the signs, GPS reminders and names on our maps and roads also remind them of this.

Thanks to the many outcomes of the Truth and Reconciliation Commission, when they go on fun school excursions, they visit fun exhibitions that are informed by our Indigenous knowledges and cultures.

They visit memorials that honour our First Nations people, including our brave Warriors and protectors of country such as Pemulway.

When they go on school excursions, the signage on the streets and highways is not only in English, but also honours the language and naming of the local First Nations peoples.

**They grow up with intergenerational hope, not trauma**

My grandchildren are growing up in a society that values them and their heritage. They are growing up with intergenerational hope, rather than intergenerational trauma.

They are relative strangers to the experiences of racism that were part of the daily experience of their ancestors over so many generations — including for me, my parents and my children.

The health professionals of the future are learning, from their earliest days, when they first set step into early childhood learning and development centres, about cultural safety. Not that they call it that any more.

Cultural safety has become so embedded into all systems that it has become the norm – rather than something exceptional that people have to learn when they start training to be a nurse or a doctor.

In 2037, cultural safety doesn’t begin in the health system; it begins in our homes and schools. It is evident in our private conversations, and our public debate and discourse.

In 2037, there is no longer a disconnect between public and political discourse – and the language used in the education and training of health professionals.

Politicians of ALL persuasions now understand – just as well as do ALL health professionals – that racism is an attack on people's health and well-being, and our capacity to live productive, self-determining lives.

In 2037, cultural safety has become a societal norm. The cultures, knowledges and practices of Aboriginal and Torres Strait Islander people are central to the national narrative; they are valued and respected.

We have fixed the “racism problem”. Embedding cultural safety into all aspects of society has helped us to transform Eurocentric systems and worldviews.

In 2037, I no longer feel the need to put on my heavy “armour” when I venture outside of my home. It’s a far cry from 20 years ago, when this armour was part of my defence system against the everyday insults of unconscious bias born of racism. Experiences such as deflecting or swallowing hard when I hear:

- ‘You’ve done well for yourself’
- ‘Aboriginal people get so much given to them’
- ‘You’re too pretty to be Aboriginal’
• ‘Yes, but you’re not like the rest of them, you’re different’
• ‘You’re not a real Aboriginal, you’re a half caste’
• or being asked to see my receipt at Woolworths self-serve because ‘they’ve had problems with my sort of people’.

In 2037, I know that when non-Indigenous people see me in the street or at work, their first reaction will not be of prejudice or fear, but of gratitude and pride.

This reflects their understanding of the profound value that Aboriginal and Torres Strait Islander peoples and cultures bring to Australian society.

**We have closed the gap in health outcomes**

In 2037, when my grandchildren get sick or need to go to the hospital, I no longer even think to worry about whether their care and treatment will be respectful.

No longer do my people leave seeing a doctor or visiting a hospital to the last possible moment because of the fear of being humiliated or traumatised.

The real-time reporting of national safety and quality healthcare data shows that cultural safety is now so embedded across all health systems that Aboriginal and Torres Strait Islander patients are as likely as any other Australians to have proper access to respectful and appropriate care.

The Health Barometer – which was established some years ago to measure our health outcomes, race relations and the cultural safety of health services, programs and policies – has become redundant.

The dual governance boards which Local Area Health Networks established to eradicate racism at the organisational and direct service delivery level are also no longer needed.

There is no longer a gap between the safety and quality of healthcare provided to Aboriginal and Torres Strait Islander people and that provided to other Australians. Our health status is now comparable with other Australians.

The health sector has long ago acknowledged its role in colonisation and such traumatic practices as removal of children and the medical incarceration of Aboriginal and Torres Strait Islander people. Nursing and midwifery now learn this history at the same time as learning about our founders, for example Florence Nightingale.

Health professions and systems have apologised and provided reparation and justice for harmful practices.

Over the past 20 years the sector learnt how to be part of healing, rather than causing harm.

The persistence, hard work and brilliance of our Indigenous health leaders paved the way for a sea change that became evident around the time this century celebrated its 21st birthday.
Climate change prompted a global sea change

I must admit that things were looking pretty grim in the years leading up to 2021. We were still dealing with the aftermath of President Trump, fake news, climate deniers, and the rise of nationalistic, xenophobic movements.

But as the impacts of climate change started to hit – earlier and harder than expected – there was a profound sea change around the world.

People realised the limitations of the usual Western ways of doing business. Globally, Indigenous knowledges were not only legitimised, but valued and centred in responses to such complex problems as climate change; social and economic inequality; and the protection and management of land and water resources.

As new social and economic structures emerged in response to these challenges and in response to what was then called the Fourth Industrial Revolution, the voices of Indigenous peoples were heard – not only in Australia but also globally.

Our ways of doing business – informed by practices of respect, reciprocity, caring for country, and relationship-based ways of working – are now centred.

Power no longer rested in self-interested hierarchies but became de-centralised. People and organisations were valued for what they could do for the well-being of the community and the planet.

Just imagine what a wonderful difference this has made for rural and remote people and communities!

At the same time as these wider shifts were occurring in society, some fundamental shifts were occurring in health systems.

The health system changed its way of doing business

It wasn’t just that the Aboriginal and Torres Strait Islander health plan was fully resourced and implemented – and that this became remembered as one of the landmark achievements of Minister Ken Wyatt, along with establishment of the National Aboriginal and Torres Strait Islander Health Authority.

It wasn’t just that the Rural Health Commissioner’s role was reformed – after some sustained, behind-the-scenes lobbying – to ensure that the Commissioner had a more wide-ranging and meaningful remit.

It wasn’t just that in the wake of the abolition of the Indigenous Advancement Strategy, the Goodes Government set up a Productivity Commission for
Indigenous Health. This quarantined money so that we were able to self-determine the way we invested in our health. And what a difference that made!

It wasn’t just that insurance laws were changed and health systems were reformed to enable women, both Aboriginal and non-Indigenous women, to birth on country.

It wasn’t any one of these changes alone that led to us closing the gap in life expectancy and health outcomes – years earlier than we had hoped for in our wildest dreams.

It was these things, but it was more than this.

When I look back now, it seems incredible that most of our health dollars and efforts were once spent on centralised, institutional systems of care that contributed relatively little to health outcomes for the large investment they incurred.

It now seems unbelievable that we once invested so little effort and money into providing the conditions that empowered people and their families and communities to have to healthy, contributing lives.

Such a fundamental shift occurred. As Indigenous knowledges and practices were centred in wider systems, so too did the health system change its way of doing business.

The mainstream health system learnt from the successes of the Aboriginal community controlled health sector. The mainstream re-oriented itself around our ways of doing business – to focus on primary health care, communities, prevention, social justice, and the social and cultural determinants of health.

Health services moved towards providing long-term contracts and seamless services addressing peoples’ needs for inclusion, housing, transport and integrated care.

For our members at CATSINaM, the changes have brought profound transformations to the way they work and how they are valued.

Our members now work at their full scope of practice. They are involved in diagnosing and managing dental caries, for example, while dentists are incorporating population health strategies into their daily work. Their work has been funded for many years now by ....the sugar tax (dare I say this in Queensland?).

It is so thrilling too to see that the mainstream politic has learnt from the ingenuity of Aboriginal and Torres Strait Islander peoples. Creativity and innovation are not only valued — but properly funded and rewarded.

After its unpromising early years, visionary leadership transformed the NBN to provide equitable access to connectivity right across the country.

Aboriginal and Torres Strait Islander people capitalised on this opportunity, supporting our creativity, entrepreneurialism and innovation. We used the NBN to drive innovation in healthcare and health promotion, as well as to contribute to a better future for all.

We are all making history right now

As I stand before you in 2037, I am not only happy, but I am proud.

One of the highlights of my career has been working to use the virtual world – cyberspace – to embed cultural safety, not only into the training and education of all who work in the health system – but also into
wider societal systems. Along with my newly released cookbook, written in conjunction with the CWA, of course.

As we contemplate this potential future together now from our present reality in 2017, let us remember that history is not something that happens in the past.

It is happening right now. We are all making history right now.

Over the next few years, as we move to embedding cultural safety into our systems and services, supported by the forthcoming Version 2 of the National Safety and Quality Health Service Standards and CATSINaM’s current campaign to have cultural safety embedded into our Health Practitioners legislation, let us ensure that this brings meaningful improvement to rural and remote health services.

Let us remember that cultural safety is a philosophy of practice that is about how a health professional does something, not simply what they do. Its focus is on systemic and structural issues and on the social determinants of health.

Cultural safety is as important to quality care as clinical safety. It includes regard for the physical, mental, social, spiritual and cultural components of the patient and the community.

Cultural safety represents a key philosophical shift from providing care regardless of difference, to care that takes account of peoples’ unique needs – and to be regardful of difference.

For Aboriginal and Torres Strait Islander health, cultural safety provides a decolonising model of practice based on dialogue, communication, power sharing and negotiation, and the acknowledgment of white privilege.

These actions are a means to challenge racism at personal and institutional levels, and to establish trust in health care encounters.

Culturally safe and respectful practice therefore is not about learning about Aboriginal and Torres Strait Islander peoples – in fact you can never know this.

Cultural safety requires having knowledge of how one’s own culture, values, attitudes, assumptions and beliefs – influence interactions with patients or clients, their families and the community. Being aware of our racial orator.

As we contemplate a culturally safe future from our current vantage point, let us reflect upon how each and every one of us can contribute to making this future that I’ve shared with you today a reality.

I’d like to conclude this presentation by inviting you to journey with me into the future. I ask each and every one of you to think deeply about how you might contribute to creating this future.
How can YOU help to make history?

Here are some suggestions:

- Embed cultural safety in your organisation’s strategic plan, and Reconciliation Action Plan.
- Make anti-racism practice part of your everyday – whether you are at home or at work – and whether anyone is looking or not. Enact zero tolerance for racism.
- Ensure your governance structures reflect the communities who you are serving. Privilege the voices and the wisdom of Aboriginal and Torres Strait Islander people and organisations.
- Inform yourself about 18C and Constitutional Recognition.
- Inform yourself about climate change and the actions you can take – and try to put aside non-Indigenous lenses when doing this. Learn from us about caring for country.
- Practise trust, respect and reciprocity. Build and value your relationships with us.

In 2037, let us look back on this conference – and this moment – as a time when we stood together, determined to make history and to create a better future.

Because today is tomorrow’s history – be brave.

Thank you.

See here for the rest of our coverage of this event.

See also this story from the CATSINaM conference: Australia’s nurses/midwives consider call to apologise for harms to Indigenous people
Romlie Mokak wraps up #ResearchTranslation17

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 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 in 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](#).

See [here](#) for the rest of our coverage of this event.
The “suburbanisation of disadvantage”: a critical concern for public health and planning sectors

The suburban dream has turned into something of a nightmare, as growing inequality and the concentration of disadvantage in the suburbs have become critical health concerns that warrant public health policy intervention, a conference in Sydney has been told.

Speakers at the annual forum of the UNSW Centre for Primary Health Care and Equity (CPHCE) made a strong argument for injecting health equity considerations into urban planning, reports Amy Coopes for the Croakey Conference News Service.

(Read her preview of the forum here).

Amy Coopes writes:

A dramatic “suburbanisation of disadvantage” has occurred in Australia, as the widening gulf between rich and poor reveals a stark spatial and geographic dimension to inequality and health, a forum heard in Sydney.
The unique event, run by the UNSW Centre for Primary Health Care and Equity (CPHCE), explored the idea of “health environments”, bringing together urban planners and health professionals to discuss the intersection of these two disciplines.

Headlined with a keynote address on *Inequality, Wellbeing and the City*, delivered by UNSW City Futures Centre director, Professor Bill Randolph, the program ranged across topics including Sydney’s *Green Square* residential mega development, the arrival of capitalism to the remote Himalayan kingdom of Bhutan, and a “healthy airports” push for Sydney’s new terminal at Badgerys Creek.

Associate Professor Ben Harris-Roxas, from CPHCE’s South Eastern Sydney Research Collaboration Hub (SEaRCH), said urbanisation had been human history’s standout trend for the last century, if not millennium.

It was a phenomenon that had now touched the furthest reaches of the globe, was accelerating – with 66 percent of the world’s population to live in cities by 2050 – and had significant implications for health.

Fittingly, given the historic and ongoing impacts to First Nations people of this process, the forum commenced with Muruwari man Mathew Doyle performing a healing song on the yidaki as part of his Welcome to Country.

**A sprawling sickness**

Though not immediately thought of as sister disciplines, Randolph said urban planning and public health had shared origins (Edwin Chadwick and John Snow) and – after a post-war period of divergence – were dovetailing once more.

Michael Marmot had demonstrated an explicit link between inequality and health, with the latter spatially determined and correlated, and Randolph said his own work had shown distinct correlations between geography, disadvantage and wellbeing.

“Rising inequality does not take space in a geographic vacuum,” said Randolph.

Australia had seen what he described as the “suburbanisation of disadvantage”, where lower income groups had been squeezed out of the inner city by income polarisation, and the private rental market – not social housing – was a key driver.

The media described this effect as – variously – the “latte line”, the “Red Rooster line”, the “goats cheese curtain” or the “smashed avocado index”, but Randolph said there were serious consequences underlying this “us and them” rhetoric, including real divides in educational outcomes, active transport or access to healthy food.

“Urban sprawl has not brought better lives for many, and health is just one dimension,” said Randolph, citing a growing gap between rhetoric and its delivery.

“Who you are and what you can afford are critical questions in whether you benefit.”

Obesity and problematic alcohol consumption were “suburban crises”, while self-assessed wellbeing was almost perfectly negatively correlated with private health insurance status (in and of itself a luxury of those with higher incomes), he said.
Looking ahead, the heat island effect of climate change would disproportionately impact lower-income areas.

A three-year project looking at some of the most disadvantaged SEIFA deciles in Sydney and Melbourne had revealed less than 20 percent were just making ends meet, while more than five percent were in “deep poverty”, having to skip meals, leave their homes unheated or cooled and pawn belongings for cash.

This was occurring against a backdrop where the top 20 percent of Australians now earned half the country’s income and held 62 percent of its wealth, while a new precariat was emerging without job security or a safety net.

The decentralisation of disadvantage meant poorer groups were segregated from jobs and services, and either could not afford or were curtailed in their ability to travel due to lack of transport infrastructure.

Women were especially vulnerable due to the “spatial leash” effect, said Randolph, also pointing to an emerging “Generation Rent” locked out of the property market.

From a service provision perspective, the scattering of those most in need over a vast geographic area was a challenge, and Randolph said he wasn’t optimistic about the future given planning and renewal remained focused on the inner city.

(See our interview with Bill Randolph on his CPHCE keynote here).

There was also significant diversity between disadvantaged areas, with implications for policy, and need for a sensible debate on a settlement strategy on where people “ought to or could live”, he added.

Eamon Waterford, from the Committee for Sydney, said sprawl was a significant issue for the city with enormous implications for health, yet was a “major conversation nobody wants to have”.

Density done well

With Sydney in the grips of high-rise construction fever, there were real questions about quality of life and implications for health, the forum heard.

Allison Heller, Manager Social Strategy at the City of Sydney, said there was such a thing as “density done well”, delivering amenity, walkability and proximity.

But living on major roads and traffic routes was a concern for health, as was ensuring people experience community and connectedness and that children and families were provided for, she explained.

The City had engaged CPHCE to conduct a health impact assessment on the draft infrastructure strategy and plan at Green Square, a 61,000-resident, 278 hectare, $13 billion mega development between Sydney’s CBD and airport, and Australia’s largest urban renewal area.

The HIA, conducted by CPHCE’s Health Equity Research and Development Unit (HERDU), looked at four main dimensions: affordable housing, community infrastructure, transport, and child health and development.

Presenting on the latter, Associate Professor Jane Lloyd, from HERDU, said “child-blind planning” meant the needs of young people and their families were all too often overlooked in high-density developments.

By 2030, 7,000 children are expected to be living in Green Square, and Lloyd said the first three years were critical for social, emotional and cognitive development, school readiness and health outcomes.

Seemingly simple things had been found to make a big difference in raising a child in high-rise environments, including ample space, storage, soundproofing and outdoor play areas.
Lloyd identified two kinds of risks for children in Green Square – those in the external environment (limited access to physical activity and walking, exposure to roads, no local primary school), and those in the internal environment (suppression of expression and exploration due to fears about noise, burns and injuries due to poorer maintenance standards in private rental properties).

Young families in rental properties, those with language barriers (with a large Mandarin-speaking population projected) and those with children with a disability were most at risk.

In concert, these factors left the child residents of Green Square vulnerable to overweight and obesity, sleep disturbances, traffic injuries, parental stress, behavioural and development problems, stigma and poor self esteem.

To mitigate these risks, HERDU had made a number of recommendations to the City of Sydney, including construction of a local school within walking distance, local daycares with multilingual staff and age-appropriate playgrounds including wild places. Delivery of health services would also be a challenge, with a linguistically diverse and disconnected population and limited infrastructure.

Pam Garrett, director of planning at the Sydney Local Health District, said intersectoral collaboration was vital to ensuring the social determinants of health were considered in the Green Square rollout, citing the lack of a school plan as one example.

Professor Peter Sainsbury, former director of population health at the South Western Sydney Local Health District, condemned the fact that there was no school, and that unmitigated suburban sprawl had gone unchecked as a “failure of government”.

**Happiness and blue-sky thinking**

The link between health and happiness had been shrewdly captured by officials in the tiny, landlocked Kingdom of Bhutan, where proposals had to meet a Gross National Happiness index similar to the health in all policies framework, Harris-Roxas told the forum.

A democracy for just 12 years, Bhutan was seeing astonishingly rapid changes as globalisation prised open its borders, and CPHCE – through the WHO’s southeast Asia regional office – had been commissioned to conduct an HIA of an industrial estate expansion on the border of India and West Bengal.

As trade routes opened up, there was a real concern about bottlenecks, with traffic jams stretching back into India, he said. Cultural conservation was also an issue, with a Buddhist monastery located on the grounds of the estate.

With a series of similar new estates planned for rollout over the next 10 years, the Bhutanese government was anxious to explore how expanding trade links could be done in a way that was sustainable for health, and happiness.

Very much a local-led collaboration, Harris-Roxas said the process had been about capacity-building rather than top-down solutions, highlighting the importance of time and intersectoral approaches, shared learning, and the value of ‘reverse innovation’.

**A new focus**

Health environments was a new research stream for CPHCE, and Sainsbury said it was an important dimension in understanding the social determinants of health.

Far from just bricks and mortar, he said the built environment reflected social relationships and power structures. In a practical sense, it also had the capacity to foster or infringe on wellbeing.
Focusing on the new Western Sydney Airport at Badgerys Creek, Sainsbury said CPHCE was exploring how to reframe debate and thinking over transformative new infrastructure to encompass – and be driven by – the potential for health.

This work was part of, and would inform, a global ‘Healthy Airports’ push, where new terminals and retrofits and their surrounds – the ‘aerotropolis’ – satisfied certain standards for health.

Some of the important dimensions identified so far in scoping work of the literature included the environment, ecosystem and economy, community and participation, heritage, form and design, transport, experiences and resources, services and facilities, health hazards and public health and health care.

Concluding proceedings were the Centre’s annual awards, with the City of Sydney’s Green Square unit taking out the health impact trophy, the NSW Refugee Health service recognised as best organisation, and former NSW Chief Health Officer Greg Stewart taking the individual prize for his ongoing advocacy work.

The forum ran hot on social media, trending Australia-wide, reflecting keen interest in the overlap of planning and health, as is also being profiled in Croakey’s new #LookingLocal series.

See here for the rest of our coverage of this event.
Some big questions about life and death: challenging “conveyor belt” of Western medicine and wishing for a loving end

**Marie McInerney writes:**

Should “bad deaths”, where people suffer unnecessary pain and distress or needless and harmful medical interventions, be pursued in the courts as violations of human rights?

Is palliative care failing its mission if it doesn’t go far beyond supporting those dying in our hospitals, homes and hospices to challenge the staggering number of deaths caused by hunger, environmental injustice, and female infanticide?

Does humanity itself need palliative care in an era where the planet’s health is in crisis?

And when we talk about ‘good deaths’, what do we mean?

These were some of the challenges put to the Australian Palliative Care Conference in Adelaide, in a powerful and provocative keynote address by **Dr Alex Jadad**, Professor at the Institute for Global Health Equity and Innovation at the University of Toronto.
The Colombian-born physician and educator had already made a splash at an earlier conference event, describing in glorious and gory detail how he recently helped his 25-year-old daughter give birth – “unexpectedly with bare hands” – in the corridor of a building.

He despaired at the “over-medicalisation of everything” that has led to an 80 percent Caesarean rate in the Colombian region where his daughter lives and helped breed a “myth of immortality” in Western nations that are losing community connections, separating body from soul, and fearful of death.

“If we brought someone here from 100 years ago, they would say ‘What have you done to yourselves!’” he said. “I think we need to be embarrassed.”

As he roamed the stage for an hour during his keynote, inviting questions, comment and coaching from the floor, Jadad did a quick poll.

Raise your hand, he invited the 800 delegates in the convention hall, if you would like to die as your patients are now.

Just four did.

“Wow,” he said. “I could stop here.”

**The final assault**

The result echoed a conference discussion led by Ken Hillman, Professor of Intensive Care at Liverpool Hospital in Sydney, who has recently published a book, ‘*A Good Life to the End*’, on taking control of our inevitable journey through ageing and death.

Hillman despaired of a “conveyor belt” that is pouring frail, elderly people with multiple problems into intensive care units in the last few weeks of their lives, where they are more likely to be over-treated and face death without dignity.

“Hardly a ward round goes by that one of our team doesn’t say ‘please don’t let this happen to me’, so it’s extraordinary that we’re doing it to other people,” Hillman said.

He quoted leading US geriatrician James Goodwin, who said:

> Overtreatment of 50-year-olds is mostly a matter of inconvenience and waste, whereas overtreatment of 80-year-olds borders on assault.

In his keynote, Jadad proposed that “a bad death be considered a violation of human rights”.

While he didn’t expect health professionals to march governments off to court or The Hague, he said they should consider whether they should rightly sue governments for continuing poor treatment of people in the final hours or days of their lives.

Around the world, he said, about 80 percent of people are dying in institutions like hospitals and aged care facilities when the same number would like to die at home.

A “huge proportion” are dying unnecessarily in pain in countries like Canada and Australia, where vets get three times the training on pain management than doctors or nurses, or elsewhere where government regulations make it difficult to access painkillers. He said:

> I’m not saying we should do it (go to court) but I’m wondering, because I think we are too nice and we have become accomplices most of the time.

> We keep witnessing bad deaths, (and we blame) ‘the system’, ‘the government’, ‘the perverse incentives under which I operate’….
What happens if we start thinking in those (human rights violations) terms instead of how I’m going to deal with this case in front of me, or the community that I have committed to support.”

Broaden the discussions about death

Just as powerful was Jadad’s challenge to the health and palliative care sector to think more globally about its concept of a ‘bad death’.

He showed a slide with the World Health Organization’s list of the top ten causes of death of the 56 million people who died worldwide in 2015, led by heart disease, stroke, and lower respiratory conditions, describing it as “one of the greatest expressions of medicalisation of death. We die with a label given by medicine.”

What would happen, he asked, if we looked through a different lens, and looked at other data sets about death?

Nearly 13 million are linked to the environment, through air, water and soil pollution, chemical exposures, climate change, and ultraviolet radiation which the WHO says contribute to more than 100 diseases and injuries.

“What do we do with this?” he asked delegates. “What’s our role, and there’s a lot of greed involved here and a lot of government complicity to allow this to happen.”

Eight million die each year of hunger, including 21,000 children every day, in a world with an abundance of food, he said.

“Isn’t that a bad death that can be prevented?” he asked, quoting former United Nations Special Rapporteur on the right to food as declaring in 2002: “Anyone dying from hunger was dying from murder.”
“Is that part of our scope?” he asked.

And what of those millions who die through **medical error**?

He pointed to a 2012 documentary ‘*It’s a girl*’ – “the three deadliest words in the world” – about millions of girls who are killed, aborted, and abandoned in India, China and many other parts of the world simply because they are girls.

Should that trouble palliative care professionals when they come to conferences, he asked, just as much as finding out how to relieve pain, or improving the efficiencies of their team, to learning how to advocate change to governments?

And then what of the renewed nuclear threat? He said:

> **We are the people who know more about death and dying than anyone in the world. What kind of provisions are we making (about that), what kind of statements are we issuing?**

> **If there is one group of people that has legitimacy to talk about death and good death and how to avoid bad deaths it is us.**

> **What are we doing, (are we) looking at our navels, (asking) how many milligrams of this do we need, how many beds do we need, are nurses valued enough? How can we advocate to the politicians around us when the world is falling apart around us?**

These questions are the underlying focus of a (paywalled) article he recently published in the European Journal of Palliative Care, after it was knocked back by many other journals.

Co-authored with Canadian Professor Murray Enkin, the article asks whether hunger, disease and poverty are really only symptoms that our “human world is terminally sick”. It says of the world:

> **We have reluctantly come to accept our individual mortality and to embrace palliative care when cure is beyond reach.**

> **What if it is time to think of palliative care for our collective humanity?**

(Access to the article, *Does humanity need palliative care*, can be requested via ResearchGate.)

**Aspirations for a good death**

Jadad told delegates that a survey of healthcare workers in a network of Colombian facilities has asked: how would you like to die?

The main responses were: to die in my place of choice, receive pain relief, and have friends and family around me.

He says that raises a number of questions: such as why do we need a specialised health system to deliver that and why doesn’t it already happen?

But it begged a bigger question for him: “Should we have higher aspirations for the biggest event of our life?”

Jadad certainly has, and he put some into practice for his 50th birthday, “curating” his own funeral and receiving a coffin as a surprise gift from his family.

He wanted to consider what palliative care might look like if we had no fear about dying: “how much closer could we get to enabling everyone in the world to experience a good death?”.
In his practice run, in an effort to remove fear and regret from his last days, Jadad sent letters of apology to people he had hurt, thanked those who had helped him, and spent intense time with his wife and children, dealing with “a lot of issues in a very explicit way, dealing with our fears about hurting each other.”

At his ‘funeral’, they closed the casket and carried him off, with his funeral music playing. That music is now set as his alarm, “so I remember, when I wake up, that I could have been dead, and I need to experience whatever the day is going to show me in the most intense way, without fear.”

What if, he said, we were able to view death as a work of art, to go out with a bang instead of a whimper, to die happy, health and in love?

How about an institution for creative dying, a hospital for delightful dying… how about music, great food, massage, smoothies with opioids, and poetry?

What if we died in style, on our own terms, and we enabled each other to do it? What if we viewed death as a work of art? That’s a conversation I hope we can have.”

There’s much more to watch and consider.

Watch his full presentation at this link.

See here for the rest of our coverage of this event.
Courageous Conversations at #ResearchTranslation17

Summer May 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.

See the interview here.

Renowned Māori health researcher Sir Mason Durie at #ResearchTranslation17

Summer May Finlay talks to Sir Mason Durie about Māori experience in translating health research into health gains in Aotearoa New Zealand. See the interview here.
When a mental health unit introduced a peer workforce, what happened next?

Marie McInerney reports:

Peer worker supervisor Fiona Burton admits she was “taken aback” by the level of anxiety and hostility among some of her clinical colleagues at an adult mental health inpatient unit when plans were unveiled last year to introduce a peer workforce at Peninsula Health in Victoria.

Because the news came at a time of other changes at the health service, staff were worried that employing peer workers – workers with lived experience of mental illness, either as consumers or carers – might put their own jobs at risk or change existing roles.

But there were other issues that raised concerns about the way mental health professionals can end up thinking and talking about the people in their care, Burton told the Victorian Mental Illness Awareness Council (VMIAC) conference.

Some staff were worried about working alongside people who may not be fully “recovered” or that they might have to be “on their best behaviour” in the lunch room where they traditionally could joke or let off steam about patients.

The extent of the resistance could be seen in the roll-up by staff of the Peninsula Health Mental Health Service to education and training sessions prior to the peer workforce commencing.

The sessions were organised by Burton, the unit’s senior social worker, and occupational therapist Rohan De Mel, who were tasked to introduce and supervise the program. They had expected big interest in such a major philosophical and systemic shift to the way they worked.
"No-one came," Burton said. She told Croakey:

We’ve been in the service for a very long time, and we assumed that because of the relationships we had with people, they would be open to a new way of doing things.

We were really quite surprised and taken aback by the level of anxiety and hostility by some people about this new workforce coming."

Transformation in attitudes

The good news is that attitudes on the unit have completely turned around since, she said, with the peer workers now fully integrated in the team, recognized and respected as their own discipline and getting referrals from all staff.

How that happened was laid out in a joint presentation to the VMIAC conference by Burton and members of the team on the “challenges, learning and successes” of introducing six peer workers to the 29-bed unit at Peninsula Health on the Mornington Peninsula, south of Melbourne.

They described the pilot program, which has now secured ongoing state funding, as an “incredible journey”, with peer worker Jesse Cross detailing how they measure its impact by the heartfelt feedback to him and his colleagues from patients, families and carers:

- “You are only the second person in my life to actually get me”
- “You have changed my life”
- “I appreciate what you wrote in my file, it gave the doctor a better understanding of me”
- “It is inspiring to meet someone who has been through similar struggles and is now successfully employed”
- “It has been great to have support for the whole family.”

A family carer peer worker, Melanie Ryan, said: “We started with a lack of knowledge of peer work, a team that was concerned about how peer work was going to impact on their own roles and anxiety about integrating a new workforce into an inpatient unit.

“We (now) have an incredibly passionate workforce who are committed to providing the best for the people, family and carers they connect with.”

Changing landscape

The experience at Peninsula Health offers insights into the value of peer work in mental health, and also why Australia lags in this area compared to many other nations, the barriers to change, and the unsafe working environments that peer workers often face in mental health services.

As the recent TheMHS conference in Sydney also heard, employing peer workers in mental health is about much more than ensuring their voices are heard; it shakes up the old modes of mental health services that are based on medical management and clinician control.

Burton told the VMIAC conference, it’s not a change that can be introduced half-heartedly.

“It’s paramount that supervisors not only want to be part of the setting up of a peer program but are passionate about changing the mental health landscape and want to challenge the way we have done things in the past,” she said.
The team talked about the many issues that came up through the process, including the risk that peer workers become “inadvertently clinicalised” or that their supervisors “over-react” when a peer worker is facing challenges and think this may relate to a relapse in their mental illness rather than an everyday workplace response.

But the main challenges for Peninsula Health really came before the peer workers stepped onto the ward, Burton said.

In part, she says, this was because the program was announced while there were other unrelated reviews of positions underway.

That added to anxiety and created some resentment, with speculation that lost hours and positions were “funding the employment of the peer workforce”.

“I think you need to have a very stable organisation that’s very clear about what roles are prior to a peer workforce being implemented, so everyone feels very secure in their own positions and they don’t feel like they’re losing something,” she said.

But another big challenge was seeing that stereotypes and stigma about mental health in the general community were also evident in the unit itself, Burton said, showing a slide that declared: “We have forgotten what recovery looks like!”

The lunch room issue

In the early days, clinical staff expressed concerns about ‘ex patients’ being part of the treatment team and participating in clinical handover. “Why on earth would we have people who had been part of service now employed as peers?” was the complaint.

“One of the challenges for staff who work on an inpatient unit is that they support people when they are acutely unwell, and don’t have the opportunity to see a person change their life circumstances and progress further in their recovery,” Burton said.

And then there was the lunch room issue: what sharing it with peer workers might mean for the ways clinical staff have traditionally “debriefed”.

Burton said the unit’s lunch room, “like any lunch room”, is where staff talk about their difficult day, of their challenges on the ward.

Sometimes that involves black humour and language – she says delicately – that “isn’t as recovery and strengths-focused as you would want it”.

“People thought they would have to be on their best behaviour around the peer workers, that they might offend them with their language,” Burton said.

“My view is that if you’re even thinking that you might offend someone with your language, then you’re not using the right language.”

Focus on language

Language is a big focus for the peer program and in the unit, guided by the work of the Intentional Peer Support program in the US and Flourish Australia, that has seen them drop the word “consumer” to describe the people they care for.

Ryan explained the thinking to the conference:

> We are individuals who have been brought together, some by choice, some not. We all come with our own stories, experiences that make us who we are. Some of us have had easier paths than others to get here.
We come together and we call each other different things – patient, inpatient, client, consumer, carer, borderline, schizophrenic, nurse, social worker – and we further add to the labels that we have collected along our journey.

Many in the consumer movement for some time have raised concerns about the use of the word “consumer” as it implies choice and suggests that there is a reciprocal contract between those who provide a service and those who use a service.”

Instead, those who use the Peninsula Health service are now simply referred to as “people”.

“By changing the language surrounding mental illness we can begin to promote hope, rather than defining a person, or group of people, by a diagnosis,” Burton said.

As its next step, the unit is looking at the language it uses in handover notes and how that adds to the labelling of people with mental health issues.

Burton showed a slide to illustrate the words and terms – like “helpless” and “hopeless” – that get used as shorthand by health professionals who are working under pressure but which are essentially unhelpful for practice and can be “inflammatory”.

Burton said:

**Instead of saying that (someone) is ‘demanding’, we’re saying now to try to look behind the reason why they are being demanding – perhaps that they were distressed because they couldn’t get their phone charged.**

**We’ve got very good at doing shorthand: it’s in our notes, in our language, in our lunchroom. I think we need to look behind those words, to really understand why the person is acting the way they’re acting.”**

**Lessons learnt**

But, despite all those challenges, Burton said the Peninsula Health team got a lot right with the program, to the point that resistance in the unit to the peer workers turned around very quickly – “after about three months it was like they’d always been there”.

Having the peer workers based in an office in the unit, rather than being community based, had turned out to be “fundamental” to success, helping them to forge an identity as a “unique discipline within the broader team”.

Another was having a Nursing Unit Manager, Liam Shaw, who backed the two supervisors “100 percent” and made sure that resources were in place to support the commitment to peer work, including employing another social worker to free up Burton’s supervision time.

She also paid tribute to “some incredible peer workers who worked really hard to develop positive relationships with staff”.

“They are now completely integrated, they’re not seen as separate at all, there’s been no undermining, no negativity,” she said.

“I wouldn’t have thought this possible a year ago.”
See slides below: **What peer workers do**; and **What peer workers don't do**

See [here](#) for the rest of our coverage of this event.
Around the world in 79 days: re-writing colonial narratives

Melissa Sweet writes:

In June, Dr Doseena Fergie, an Aboriginal and Torres Strait Islander Elder and nursing academic, left Australia to travel the world in 79 days, investigating the situation of First Nations people globally.

A Churchill Fellowship took her on a “once in a lifetime experience” – meetings with Indigenous people in Italy, Finland, Norway, the Netherlands, Britain, Canada, Hawaii and Aotearoa/New Zealand (see map below).

Her aim was to explore how First Nations people had rejuvenated their sense of identity and belonging as a way of healing from intergenerational trauma associated with colonisation, Fergie told the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) conference.

The trip was healing and empowering, in documenting the importance of First People's knowledge, language, ceremonies and rituals, said Fergie, who is of Wuthathi, Mabuiag Island and Ambonese descent, and an academic at Australian Catholic University (ACU) in Victoria.

Last year she was inducted into the Victorian Honour Roll of Women for her work in nursing and community health, and was also made an inaugural Fellow of CATSINaM.
Sovereignty and healing

During her travels, Fergie observed an upsurge in self-determination as Indigenous peoples “had become a rising force and perhaps a threat to white-privileged eyes”.

She also witnessed stories of “resilience, pride and growth”, the revitalisation of languages, and greater emphasis being placed on the importance of learning about colonised history and addressing intergenerational trauma.

Fergie found organisations that wanted to work collaboratively with First Nation peoples appreciated and acknowledged openly the need to empower Indigenous perspectives and to ensure First Nations had the freedom to manage their own affairs.

“I found nations successful in closing the gap between themselves and the dominant group because they persevered in sovereignty,” Fergie told Croakey in an interview at the conference (watch it below).

“They said the way forward now was not aggressiveness but negotiation. They shared acts of kindness, the importance of truth telling, justice, healing holistically, valuing reciprocity, respecting the dignity of each individual and being responsible and nurturing our bodies, our community and our natural environment.”

Among the most moving experiences of her Fellowship were visits to the burial sites of two Aboriginal children: a boy who was interred beneath the Basilica of St Paul's Outside the Walls in Rome, and a girl’s grave in England.

The ACU this year announced a scholarship to commemorate the boy – Francis Xavier Conaci, who in the mid 1850s was sent from New Norcia in Western Australia to Rome to study in a Benedictine monastery, where he was buried in an unmarked grave.

Fergie returned to Australia with a determined commitment to work towards the repatriation of these children’s remains and their spirits.
“To research and find the ancestral remains of Aboriginal children who died 170 years ago in Europe and to repatriate them back to Country is part of healing,” she said. “To stand beside the graveside of two children who died long ago was an incredibly humbling experience.”

Valuing cultural and clinical knowledge

Addressing CATSINaM delegates, Fergie urged Indigenous health professionals to ensure their cultural knowledges were valued at least as much as their clinical competencies, and that “our cultural values of respect, caring and sharing” are not lost.

“In our universities we train people to be clinically competent but as Aboriginal and Torres Strait Islander nurses and midwives… we have a world view that is different,” she said.

“We are different from the western world. Professional skills matter, but don’t forget the culture. Go back to country, learn it, because you won’t get it in the universities as such.”

Fergie has published a report on her Fellowship’s findings, and it highlights the importance of strengths-based approaches. She writes:

The continuous murmuring of Indigenous deficit statistics like the high mortality and morbidity rates compared to their Non-Indigenous counterparts, pales into insignificance behind the forward moving models I observed. They focused on a community’s strengths.

I returned with a better understanding of the evils of colonisation and assimilation and an awareness of the inter-societal structures and political hearsay that posit an illusion of Indigenous support, but who, act counter-productively.

It seemed that when the Indigenous people and their issues became visible to that society, they were foreseen as a threat to the maintenance of the dominant rule of power. Racism and discrimination came in many subtle forms but their impact continued to be devastating. In contrast, self-determination offered strength and healing, it gave hope for a better future.”

Fergie identified several themes arising from her Fellowship’s investigations, including: the importance of relationships, respect and reciprocity; culture; language; education; self-determination; economy; and health and wellbeing.

She said great gains were being made in tertiary institutions that are solely Indigenous focussed, such as Te whare wananga o Awaranuiangi in Aotearoa/New Zealand, while the Six Nation Polytechnic in Ontario is working toward setting up a First Nation University in their state.

Fergie also cited the Windward Nursing Course in Oahu, which bases the development of cultural care for Indigenous clients by having nursing students to initially learn to care for an organic garden.

“Having Indigenous students access this program ensures that cultural knowledge and language is sustained thereby ensuring better culturally appropriate care for Native Hawaiians,” Fergie wrote.

Models of self-determination

The report provides a rich overview of the different situations of Indigenous people globally, as well as their similarities.

In Finland, Fergie visited the Sami Parliament, where she discussed the country’s proposed Truth and Reconciliation Action Plan, while in Norway she saw a Sami Norwegian psychiatric centre and mental health and substance use units called Samisk nasjonal kompetansetjeneste (SANKS), which focus on addressing the impact of intergenerational trauma.
She also learnt how the Sami in Finland and Norway have diversified away from reindeer herding into other jobs within the mainstream, including tourist businesses in Karasjok, Norway, and Siida in Finland, which educate tourists on culture, and sell cultural artefacts and goods.

In the Netherlands county of Friesland, Fergie stayed with Frisian people who are, like the Sami, white Indigenous people. She learnt about the traumas of forced assimilation, as well as how important the slave trade had been in building the country’s wealth.

In Vancouver, British Columbia (BC), she visited the Tsawwassen First Nation (TFN) community who manoeuvred a viable Treaty with BC, and the peak Indigenous Health body – the First Nation Health (FHN) Authority and the Chairperson of their Council.

She learnt that the TFN's economic viability, through the development of the TFN Mills shopping complex and real estate, was pivotal in their treaty with the British Columbian Government.

TFN has had its own Government since 2013, the Tsawwassen Legislature, consisting of 13 TFN members elected at a general election, and the Chief. They discuss and make laws, which form the principles that fundamentally organise the Nation.

The TFN Strategic Plan 2013 – 2018 states:

\textit{Twawwassen First Nation will be a successful and sustainable economy and an ideal location to raise a family... Our Government will help us achieve our goals by communicating, being respectful and taking full advantage of our Treaty powers.}

In Whistler, BC, she saw the Squamish & Li’lwat Cultural Centre, a model developed jointly by the Squamish Nation and Li’ilwat Nation that took nine years to be economically viable and self-sustainable, and that provides mentoring to 400 young people each year.

Fergie said her investigations had underscored the importance of understanding the local history of colonisation for true understanding and healing to take place. She wrote:

\textit{For instance, a gatekeeper spoke about the history of Sami alcoholism in which during the war years there were ration cards for Norwegians etc. At the time, the Sami had control of all the resources such as bush food. They knew the land and were skilled in how and where to get them. These were traded via their Scandinavian ration cards for alcohol.}

\textit{By knowing this fact this may remove the Sami ‘veil of shame and guilt’ that the dominant society had developed and stereotyped Indigenous people to be the ones at fault. There are similar stories placed on Indigenous Australians that have led to their negative stereotyping.}

In 1873, when the French author Jules Verne published his famous novel, Around the World in Eighty Days, it perpetrated many colonial stereotypes and agendas.

In 2017, Dr Doseena Ferbie took just 79 days to show how First Nations peoples are resisting, challenging and re-writing colonial narratives, while ensuring that their own narratives endure, develop and flourish.

She ended her CATSINaM presentation by urging Aboriginal and Torres Strait Islander people to apply for Churchill Fellowships – applications close on 27 April 2018.

Watch this interview:

See here for the rest of our coverage of this event.
Showcasing groundbreaking work from the Choosing Wisely front lines

At a national meeting in Melbourne, hospital and health services from across Australia showcased their efforts to cut down on unnecessary tests and procedures that can cause harm to patients and add to health costs.

The Choosing Wisely Australia event was held by NPS MedicineWise to mark the second anniversary of the initiative in Australia, which has built strong links with medical colleges and health services.

It came as Choosing Wisely is set to launch its second phase, a “marathon” focus on consumers and looking to build partnerships with Primary Health Networks.

Journalist Marie McInerney reports below on a number of successful programs and the challenges still to be addressed.

Marie McInerney writes:

For some health services, it’s as simple as taking a test off a default order form or adding a pop-up alert when a doctor is ordering one to ask if a patient really needs the test.

For others, it’s about deeper cultural change around patient care, addressing doctors’ fears about missing something crucial or being sued, or ambitious opportunities to cut back on patient stays by, for example, introducing same-day hernia repairs as standard in Australia.
For Eastern Health, which runs seven public hospitals and a range of community health facilities in Melbourne’s eastern suburbs, introducing a program to cut unnecessary pathology tests involved a combination of factors – not least keeping it interesting and fun.

That included dubbing its Choosing Wisely style program NUTs (for “No Unnecessary Tests) and running competitions that prompted the Game of Thrones meme (feature image above) – all fun parts of serious emerging theories around ‘gamification’, or the use of gameplay mechanics to make non-game applications more effective.

Preliminary work on the program got a big boost when emergency physician Dr Paul Buntine, who is now NUTs project leader, was granted six months sabbatical to dig into the literature around over-testing and look for patterns at Eastern Health.

Since then the service has seen “remarkable and sustained reductions in test requesting” through education of staff, clinical pathways and electronic decision support – including an automatic prompt asking for the name of a supervising doctor when a junior doctor orders a test that has been put on a watch list. “The day we turned that on, some of the high frequency tests dropped dramatically”, Buntine told Croakey.

According to the NUTs presentation to the meeting, the program has delivered nearly a 50 percent overall cut in testing – or a reduction of 40,000 tests a year – across its three Emergency Departments. It achieved that by targeting five high-frequency, low-value pathology tests and two scans for pulmonary embolisms that are high cost, time consuming and involve considerable patient radiation exposure.
For that, the program won the 2016 Victorian Public Healthcare awards for Quality & Safety, and funding from Better Care Victoria as it expands NUTs, with similar signs of promise, into general medicine and intensive care units.

“An organisational culture change is underway,” team member Janet Steele told the meeting.

**Bye Bye PPI**

The Sir Charles Gairdner Hospital in Perth also had a catchy title for one of its Choosing Wisely programs.

Emergency Department and Intensive Care physician Dr Matthew Anstey said the Bye Bye PPI program aimed to better manage the use of proton pump inhibitors (PPIs) for stress ulcer prophylaxis (SUP) in intensive care units amid concerns they are often used for long periods without ongoing review.

“We did a pilot project in ICU (Intensive Care Unit) and we saw we were starting a lot of people on PPIs and then forgetting to stop them when they left,” he said.

“For us the reasons to tackle this was that it’s high volume, there’s low incidence of harm but those who do develop harm do so significantly with linkage to pneumonia, dementia and nephritis,” he said. And, he said, it was a trial looking at deprescribing as a bigger topic.

The project was informed by a retrospective study of five adult ICUs in Western Australia, which found that 44 percent of patients were discharged from hospital with a PPI with no documented indication.

“This is consistent with local and international data showing a high frequency of inappropriate continuation of acid-suppressing medications,” Anstey and his fellow authors wrote last year in the journal *Critical Care and Resuscitation*.

They estimated the financial costs alone of unnecessary PPI use, extrapolated across Australia, at more than $22 million a year.

Anstey, who is chair of Choosing Wisely Australia’s Advisory Group, said Bye Bye PPI took an interdisciplinary approach, involving pharmacists, junior doctors, and nurses. It has had a significant impact in the ICUs of the five hospitals, with unpublished results indicating a 30 percent reduction in PPI prescribing.

Anstey said results for deprescribing were “not that amazing yet” but encouraging. The main intervention has been installing a mandatory field on the electronic discharge summary where instructions had to be written to the patient’s GP if a PPI was ordered.

While it can be circumvented, comments to GPs on summaries rose from zero to nearly 20 percent. It’s not yet ideal, but better than before and is showing up some of the broader challenges. “It’s the learnings on this more than the results,” he said.

**Harder to get off than get on**

As this 2012 article (by Croakey’s Melissa Sweet) explains, the forces that contribute to overdiagnosis and overtreatment include health systems that are overly focused on hospitals and specialist medicine rather than primary healthcare. Add to these legal pressures, ingrained cultural beliefs and powerful professional and commercial interests.

For Choosing Wisely, the relationship between doctors and patients, and the conversations they have, are at the heart of addressing these factors.

Its surveys reveal interesting insights, gaps and tensions about those relationships, including where GPs and specialists commonly say “patient expectation” is a major driver to over-testing and over-prescribing.
In one survey, one in four health professionals reported that they get patient demand for unnecessary tests, treatments or procedures on a daily or weekly basis.

Seventy percent of GPs in that survey reported that they always or often attempt to discourage patients from those unnecessary interventions, but they also revealed why many clinicians would still request a test, treatment or procedure even if they felt it might be unnecessary.

By contrast, only 16 percent of consumers told Choosing Wisely they ask for tests and 71 percent agreed that they have a responsibility to help reduce the use of unnecessary medical tests.

However, 75 percent then said they believed that if they were ill their doctors should conduct “all available” medical tests.

Sydney psychologist Dr Jesse Jansen provided some insights for these tensions from her project seeking to reduce the medication burden in older people.

In her presentation on “Too much medicine and not enough conversation”, she described polypharmacy (taking more than five regular prescribed medicines) as one of the most important challenges in modern medicine” that increases adverse events, reduces quality of life and costs Australia up to $250 million a year. She said it seems harder to get off medication than to get onto it.

Jansen has reported on the issue in the British Medical Journal, saying there is limited evidence to inform polypharmacy in older people, but that systematic reviews of deprescribing show that “reducing specific classes of medicines may decrease adverse events and improve quality of life”.

Her project developed a shared decision making framework for deprescribing, which identified three patient types:

• Type 1 held very positive attitudes towards medicines, preferred to leave decisions to their doctor and were resistant to deprescribing
• Type 2 voiced ambivalent attitudes towards medicines, preferred a proactive role and were open to deprescribing if their medicines were causing problems
• Type 3 were frail, perceived they lacked knowledge about medicines, and preferred to defer decisions to their doctor or companion.
Jansen said these findings led to the development of a tool to facilitate shared decision making between the older patient, a companion or carer, pharmacist and GP about deprescribing, which has shown positive results in a pilot test to date.

**Multiple strategies needed**

For consumer advocates, such results underscore the need for multiple strategies to engage with consumers from very different backgrounds, with different levels of health literacy, access to information and support, and who experience varying health at crucial times.

Employing a sporting analogy, NPS MedicineWise Client Relations Manager Dr Robyn Lindner said the Choosing Wisely campaign had focused initially in Australia on a “sprint” with health professionals and services, seeking to get a critical mass of medical colleges and other organisations on board and moving quickly from recommendation to implementation.

*With the consumer engagement side of things, it’s fair to say we are treating it more as a marathon in terms of how we are approaching the scale of work that’s ahead of us.*

Lindner and Consumers Health Forum of Australia CEO Leanne Wells will co-chair a working group in coming months to co-design strategies for a consumer engagement and activation project based around the highly valued Five Questions.

They also want to follow on from the strong relationships that Choosing Wisely has forged with eight health services that have signed up as Choosing Wisely Champions. They expect soon to announce six “vanguard” Primary Health Networks as new champions.

Wells was heartened by a call at the Melbourne meeting from Chief Medical Officer Professor Brendan Murphy for a “consumer movement” to be the next Choosing Wisely priority.

**Shifting how doctors see risk and quality**

For the health professions, a number of presenters agreed on the need for Choosing Wisely to be about culture, not a strategy, and for a shift in how health professionals and services see risk and quality.

Associate Professor Nola Ries, from the University of Newcastle’s School of Law, said doctors’ fear of being sued drives unnecessary testing and treatments – with surveys showing around 70 percent of doctors say they regularly engage in defensive practice.

“This means doctors order tests and procedures, make referrals, and prescribe drugs to reduce perceived legal risks, rather than to advance patient care,” she said.

But she said her review of Australian legal cases shows many doctors misunderstand their legal risks on two levels. First, they worry about being sued if they miss a diagnosis or treatment is delayed, when Australian courts actually discourage defensive practices.

Secondly, the legal principle of consent means that patients have a right to make informed healthcare choices. “Yet research reveals that many doctors do not adequately inform their patients, especially about the risks of overdiagnosis and overtreatment,” she said.

It’s also about changing the way doctors and health care services judge quality of care, said Dr Simon Judkins, president-elect of the Australasian College for Emergency Medicine.

He referred to a recent article published in *Emergency Medicine Australasia* by Professor Gerben Keijzers that urges “critical thinking, curiosity and parsimony” in medicine and suggests ‘doing nothing’ could be redefined as a quality measure.

“It is important to remember, more care is not better care,” Keijzers writes.
But, with Choosing Wisely initiatives delivering many financial savings, there was also a warning that policy makers and regulators should “venture carefully” and make sure that improved patient care remains the driver, not containing costs.

Dr Karen Luxford, from New South Wales’ Clinical Excellence Commission, said that pulling the wrong kinds of levers and mechanisms could end up with perverse incentives.

She recalled the decision by Medicare in the United States in 2009 to stop reimbursing hospitals for several complications or comorbidities developed during hospitalisations – described as ‘never events’ (events that should never happen).

Such regulations, she said, “can lead to gaming, and people and hospitals not accepting patients that might get them into that category”.

*We don’t want to see people not being cared for, so the levers we pull need to be very careful. What we need to look at is how to promote quality not disincentivise people.*

**Interviews from #OKtoAskAu**

**Talking with Dr Simon Judkins**

**Hearing from consumer advocates**

See [here](#) for the rest of our coverage of this event.
Calling for a minimum price for tobacco products, and action on retail licensing

Marie McInerney writes:

Australia has been urged to implement a minimum tobacco price to stop manufacturers targeting lower income smokers, and to introduce strong retail licensing to cut the number of tobacco outlets, particularly near schools and in poorer communities.

Professor Kurt Ribisl, from the School of Global Public Health at the University of North Carolina, told the Oceania Tobacco Control Conference that Australia was at the cutting edge of many tobacco control efforts, not least with plain packaging.

But he said he had been surprised to discover how much it lagged on key supply side issues, which allowed tobacco companies to circumvent or undermine other tobacco control initiatives.

Australia’s high tobacco taxes had pushed up prices and in turn reduced consumption, but tobacco companies had hit back by focusing aggressively on discount brands, producing a proliferation of these brands at the very low end of the market, he said.

To counteract those strategies, he said governments should impose a floor price or minimum price, such as about $20 for a pack of 20 cigarettes.
“That way you can really reduce the disparities where low income people smoke at a higher rate than high income,” he told delegates. “It would help to reduce that gap and have an overall effect on reducing smoking”.

Ribisl specialises in policy issues related to the sales and marketing of tobacco products at the point of sale and on the Internet and has researched tobacco product marketing, pricing, promotions, and youth access, as well as spatial mapping of tobacco outlets.

He was part of a recent study that compared the projected impacts of a cigarette floor price and excise tax policies on socioeconomic disparities in smoking in the United States.

The simulated study projected that state minimum price laws set at the average reported pack price would raise prices by $0.33 and reduce cigarette consumption by about four percent, while minimum prices set at $2 higher would reduce consumption by 16 percent.

He is now part of a follow up study “to test the real world impact, which we assume will match what the simulation has found,” he told Croakey.

That study will look at New York, one of the few places in the world to have introduced minimum prices. The city has also banned price discounting, “so there’s no ‘buy one, get one free’, “ he said.

Ribisl conceded that a minimum price, unlike tobacco taxes, had one disadvantage in that it can increase profits for the tobacco industry – a “small side effect” that had caused some in the tobacco control sector to oppose the move in the past.

But he urged delegates to keep their eyes on the public health goal of reducing tobacco consumption, amid long established evidence that price increases are the most effective tool to discourage smoking, with each 10 percent price rise generating a four percent reduction in smokers.

“We get fewer kids smoking, more people who smoke quit, and also the people who continue to smoke, smoker fewer,” he said.

Weak on tobacco retail licensing

Ribisl said Australia’s weak tobacco retail licensing laws had been “one of the bigger surprises on my trip here”.

“In so many areas you are so ahead of the rest of the world, with plain packaging, strong pictorial warnings, high taxes, but (that’s) an area you’re really falling behind in,” he said, noting that it was a very strong and popular area of regulation in the United States.

Scott Walsberger, from Cancer Council NSW and who chaired the session addressed by Ribisl, wrote recently that licensing of tobacco outlets is the most commonly advocated measure in Australia for reducing tobacco availability.

“It can be used to track the number of outlets selling tobacco, and to regulate the availability of tobacco by limiting the number of outlets that receive a license, reducing the density of outlets within areas, and potentially limiting the type of outlets that can sell tobacco,” he said.

But currently, he said, New South Wales only has a notification scheme in place – whereby tobacco retailers simply need to let the government know that they sell cigarettes.Victoria and Queensland have no licensing system, and Ribisl said that other states have modest licensing systems but do not make the most of them.

He said an immediate benefit of licensing was that it persuaded some operators, who did not want to pay fees or comply with regulations, to stop selling tobacco.
But there was also the opportunity for “add-ons”, built in regulations such as banning outlets from selling tobacco if they were within one kilometre of a school, stopping them from selling particular products such as menthol cigarettes, or refusing a licence if they were too close to another tobacco outlet.

**Built environment matters**

Ribisl said evidence showed the built environment matters for smoking rates.

“There are a whole series of reasons why greater retail density is bad,” he said. “If you live with 250 metres (of a tobacco outlet), you’re more likely to relapse.”

Other studies have shown that children are more likely to smoke when there is greater retail density near schools.

He recommended five ways to reduce the density and number of tobacco outlets, based on this research into how US communities can take action through legal and policy approaches.

They are:

1. Cap the number of retailers in a geographic area.
2. Cap the number of retailers relative to population size.
3. Require a minimum distance between retailers.
4. Prohibit retailers from locating near schools or other youth-sensitive areas.
5. Prohibit sales of tobacco at particular store types.

“We don’t allow strip bars, gun shops or lead smelting plants near schools… but we do freely allow most jurisdictions to sell tobacco near schools,” he said.

**Retailers’ perspectives**

Organisers of the conference described supply side issues as the “hot topic” for policy makers, as a number of the concurrent presentations detailed.

One study looking at bars, pubs and clubs in New South Wales and their views on selling tobacco suggested that industry resistance to restrictions on tobacco sales in licensed premises may be less than anticipated, the authors said.
It also produced further proof of the high density of outlets in Australia. Forty one percent of those surveyed said the nearest alternative provider of tobacco was within 500 metres while 80 percent said the nearest was within one kilometre.

Lead researcher from Western Sydney University Professor Suzan Burton said more of the surveyed outlets that sold tobacco rated cigarette sales as “unimportant” than “important”.

“When asked their reaction if cigarette sales were banned in licensed outlets, direct concerns about lost profit were raised by less than 10 percent, reinforcing other evidence that the profit from cigarette sales is low for many retailers,” Burton said.

Overwhelmingly, she said, they could imagine not selling cigarettes and more than 20 percent said they expected a ban within five years.

But a study of convenience stories, or dairies as they are known, in New Zealand showed that it might be different for such outlets where tobacco may not be a great profit winner but is seen to contribute significantly to turnover and, importantly, dictate whether a customer uses one particular store over another if they need cigarettes.

Martin Witt, from the Cancer Society in Canterbury and West Coast said the majority of owners and manager of stores involved in face to face interviews saw tobacco as important to their livelihood and were “either ‘OK’ about selling tobacco or gave little thought to its sale”, although security concerns were an issue.

But another New Zealand study raised some of the tensions involved for retailers, who want to protect their business interests, but may have had their own losses through smoking related cancer, worried about exposure of children to tobacco, or could see the impact that tobacco consumption had on poverty.

Lindsay Roberston, a Research Fellow at the University of Otago, led the study into how New Zealand tobacco retailers view measures to regulate tobacco retail availability, including mandatory licensing.

The responses were mixed: from “just a money grabbing tax” to “as long as there’s a good reason”. Some welcomed the general idea of reducing retail availability, seeing it like necessary alcohol restrictions, while others emphasised personal responsibly and “shunned ‘nanny state’ interventions”.

Robertson said interesting responses came when the researchers probed more specific policy options, such as restricting the sale of tobacco around schools.

“About half either supported or accepted the idea of restrictions around schools, suggesting where, if the rationale is clear and includes protecting children, retailers are more likely to support regulation,” she said.

This helped to identify the policy approaches that could be seen as more acceptable for tobacco retailers, she said.

“Many retailers don’t like tobacco, don’t like selling it, but feel they have to (for business reasons),” she said. “That opens the possibility for regulation.”

The New Zealand SmokeFree 2025 initiative (which the conference has been told has lost momentum), is encouraging Tobacco Free Retailers, arguing that tobacco is more available in our communities than bread and milk even though it kills half the people that use it regularly (see its toolkit to help communities talk retailers into signing up).
Watch this interview

See here for the rest of our coverage of this event.
Ten powerful points for the health sector: lessons from #LBQWHC17

Presentations and discussions at the Lesbian, Bisexual and Queer Women's Health Conference in Sydney revealed significant gaps in the health sector in policy, research, practice and knowledge.

Amy Coopes identifies the top ten lessons out of the conference for the health sector and wider community.

1. Smoking is a major problem in the LBQ community

Australia may be a world leader in efforts to curb smoking, but mainstream campaigns are not reaching the lesbian, bisexual and queer community, with tobacco use 2-2.5 times higher than that seen in the broader populace: 30 percent overall and a staggering 42 percent of 16-24 year olds, according to the latest SWASH survey.
This is a major failure in public health terms.

Why do LBQ women smoke?

- Internalised homophobia, minority stress, discrimination and bullying, isolation, polydrug use, a community culture of smoking

- Additional risk factors: lower levels of education and income, more likely to report regular binge drinking and illicit drug use, more likely to have experienced anti-LGBT harassment and to have received a mental health diagnosis

Why are current campaigns failing?

- There is no mention of LBQ women at the national policy level, despite data showing 74 percent of LBQ smokers want to quit, 73 percent had tried in the past year, and only 16 percent had never tried to kick the habit

- Mainstream quit models like Narcotics Anonymous do not resonate with LBQ women due to theist overtones, are not safe or relevant spaces

- Within the LBQ community smoking is seen as a cultural norm; outside the community there are implicit biases about smoking as a crutch for trauma

- With the exception of ACON’s Smoke Free Still Fierce initiative, there are no campaigns targeting and featuring LBQ women, and no funding for this work

- Most GPs and those working in public health and policy simply don’t understand that this is a significant issue for the LBQ community
What might work better in this space?

- Peer support programs linking LBQ smokers to LBQ ex-smokers – a role model who can answer questions, provide accountability and guidance
- Community-conceived, driven and led campaigns with positive messaging, elevating LBQ voices and faces
- Targeted approaches appreciating the diversity within the LBQ community and engaging partners such as LGBTQI sporting clubs
- FUNDING.

Check out ACON’s Smoke Free Still Fierce resource hub here.

2. Everyone with a cervix needs a Pap test

Despite years of concerted education and campaigning, one in five LBQ women have never had a Pap test, and women who had never had sex with a man remain 2.5 times more likely to have never been screened, according to SWASH.

Myths persist among health care workers about lesbians not needing cervical screening, and there are significant barriers for trans and gender diverse people including dysphoria around those parts of the body, the fact that the test is designated as being “for women”, and previous traumatic experiences with the health system.

In response to this, ACON will be rolling out a new awareness campaign ‘At Your Cervix’ to increase screening rates among the LBQ & TGD communities, including sensitivity and awareness training for health workers and a community-run STI screening clinic in Sydney. At Your Cervix will launch in December, to coincide with nationwide changes to the cervical screening program.

Its central message? Everyone with a cervix needs screening.

Watch our interview with At Your Cervix project lead Amie Wee, and check out her conference presentation At Your Cervix.

3. Beyond the binary: boxes don’t capture bodies don’t capture beings

Asking someone to check a box on some of the most fundamental aspects of their being is worse than reductive — it can be oppressive, offensive, even obliterative. Categorisation of gender (binary or otherwise) cannot capture the spectrum of human diversity, in body, desire, relationship or sexual practice. Each is distinct, diverse, and differ from person to person, reflecting a spectra of possibilities.

In simple terms:

- Gender is part of how we make sense of ourselves and is situated across spaces of femininity and masculinity. Gender identities are typically female, male, neither or a combination of the two, and identity isn’t contingent on any medical or legal transition. Gender experiences might be cisgender (identifying with the gender we were assigned at birth) or transgender (identifying to a different gender then what we were assigned at birth).
• Though commonly conflated, bodies are not synonymous with or prescriptive of gender (or vice versa); any and all genders can have any and all physiologies

• Concepts of self as a sexual being and identification with a social/cultural group (e.g. straight, gay, lesbian, dyke, bisexual, queer, pansexual, asexual and many others) may not capture all the desires, relationships and sexual practices people experience and prefer.

• This is critical in sexual history-taking, public health campaigns, policy development and respectful, safe, appropriate research.

According to SWASH, identities within the LBQ community have shifted over time, with more and more women identifying themselves as queer rather than lesbian, particularly in younger age groups, and exclusive attraction to women the experience of just one in three.

Of note, two thirds of LBQ women surveyed by SWASH said they had ever had sex with a man – 1 in 5 reported doing so in the previous 6 months (and 38 percent often did not use protection). This underscores the importance of not making assumptions about sexual behaviours based on identity.

Attitudes and language translate into very real health outcomes, determining whether LBQ and trans and gender diverse (TGD) individuals access care, their experiences within the system and their overall wellbeing.

One study cited showed 28 percent of TGD people had experienced harassment in a medical setting, 19 percent had been refused care and two percent were victims of violence in a doctor’s office. Another study showed that 24 percent of TGD disagreed or strongly disagreed that they were treated with respect and sensitivity by service providers, and 53 percent strongly agreed or agreed that services did not understand transgender issues.

The overarching message – I’m great, but assuming makes you a bit of a donkey.

DO ask about sexual partners and practices using open and non-judgmental language, inquire about preferred pronouns and be guided by the person in front of you. DON’T jump to conclusions about bodies, gender, desires, relationships or sexual practices. NEVER intentionally misgender, use incorrect pronouns or refer to a TGD person by an old name or identity.
There are some great factsheets from the LGBTI Health Alliance, the Victorian Equal Opportunity and Human Rights Commission and resources on building inclusive health services from GLHV.

Researchers from the University of Melbourne have also developed this fantastic guide and checklist for GPs & nurses on creating LBQ-friendly practices.

4. The medical community is failing intersex people

The term intersex encompasses a diverse spectrum of variations, mostly genetic, on the medically dichotomised definition of sexual and reproductive anatomy as male/female. Despite being a part of normal human variation since, well, forever, Western social and cultural narratives and language around intersex continue to medicalise and pathologise.

Surgeries to ‘correct’ or ‘assign’ gender to intersex infants continue to be legal in Australia, despite the fact there is no evidence base or medical consensus for these procedures, rendering them little more than genital mutilation.

In March this year, a delegation of intersex people from Australia and New Zealand came together to discuss community concerns and priorities going forward, and issued the landmark Darlington Statement. As its first order of business, Darlington calls for the ‘immediate prohibition as a criminal act all deferrable medical interventions that alter the sex characteristics of infants and children without personal consent’.

Research presented at #LBQWHC17 showed that 95.5 percent of intersex people surveyed felt the surgery performed on them as children was inappropriate, reporting it had been ‘completely disempowering’ to not have been able to consent. In adulthood, 16.7 percent found sex dissatisfying as a result, with six percent reporting little to no sensation and 13.7 percent experiencing a mental barrier to sex.

Incorrect assignment requiring later correction occurred in 25 percent of all cases, and scarring left people without sensation, or infertile. Some 40 percent of intersex people who underwent such surgeries were estimated to develop severe psychological issues. Poor education among healthcare professionals, conflation with transgender and lack of intersex-specific services were also identified as issues.

Organisation Intersex International (OII) Australia’s Bonnie Hart said intersex people had huge trust issues with the health system, and questioned how, when most assignment surgeries were inherently experimental without an evidence base or long-term follow up, they could meet the maxim primum non nocere. Hart said intersex people encountered a raft of other barriers in accessing health:

- Lifetime of isolation from being told they are ‘rare’
- Conflict between raised/lived gender identity and identifying as intersex; inherent political connotations of this act
- Lack of an empowered language to demand affirmative health care, spectrum of identities and bodies beneath the umbrella of intersex making a unified voice and agenda challenging
- Inherent heteronormativity of treatment paradigms – some intersex women need mammograms and Pap tests, others require prostate care
• Poorly managed transition between paediatric and adult care
• Lack of clinical consensus on intersex variations and treatments
• Inherent pathologisation and othering of intersex by the medical system.

Hart said greater education was needed for midwives, GPs and other medical professionals on understanding that intersex was not a pathology and that such messages needed incorporation into the school sex education syllabus.

You can access the LGBTI Health Alliance resources on intersex here and OII Australia has a guide to including intersex in research studies and surveys here, along with a heap of other excellent resources. You can also catch our interview with Bonnie Hart here.

5. Eugenics and ethical dimensions of the IVF industry are not being addressed

There has been a pink dollar boom in the IVF industry as more and more LGBTQI+ people seek to have children, but the ethical implications of fertility clinic screening have been little scrutinised.

Through sperm testing or use of pre-implantation genetic diagnosis (PGD), where a cell is removed from the developing conceptus for analysis, couples are offered the opportunity to screen out a host of ‘disorders’ including trisomy 21, cystic fibrosis, haemophilia A, Tay-Sachs and Turner syndrome, along with a number of other intersex variations. Unlike sex selection of embryos, which is illegal in Australia, these screening practices are not only permitted but encouraged by clinics.

Disability rights advocate Jax Jacki Brown told the forum 92 percent of all trisomy 21 cases detected in the United Kingdom are now aborted due to stigma and assumptions around living with a disability or the supports available. She said screening out difference was grounded in the medical model of disability rather than the social model, which views disability as a construct of society and is now the globally accepted way of understanding disability.

Organisation Intersex International (OII) Australia prepared a comprehensive submission to the NHMRC on ethical issues around PGD and we’d encourage you to have a read here.

Other ethical issues discussed at the conference included:

• Declaration of same-sex couples as ‘socially infertile’ for assisted reproductive technology purposes, meaning they do not get access to Medicare rebates for the first cycle of treatment and have to pay the full cost (~$15,000) up front

• Race and donor conception, with delegates told some clinics offer couples a fast-track to the top of waiting lists if prepared to use an Asian or African-American sperm donor.

6. Discriminatory public discourse affects health

Harassment and abuse of LBQ women in Sydney has hit a 10-year high, rocketing 10 percentage points in the most recent SWASH survey period – two years dominated by vitriolic political and media debates about the same sex marriage plebiscite and Safe Schools program.

Unsurprisingly, this has been matched by an increase in the proportion of women reporting moderate to high levels of psychological distress (continuing a trend seen across the survey’s 20-year history) and receiving a mental health diagnosis.

The bottom line? Brinksmanship over whether the general public should be allowed to discuss (at length and in technicolour) and then vote on the civil rights of a historically oppressed minority is a. permissive of abuse, discrimination and vilification and therefore b. traumatic, damaging, and unnecessary.
Marriage was circumscribed as between a man and woman by parliament, without a public vote, in 2004. To pretend anything greater than this is required to reverse it is dog whistle politics with the very real potential to harm. See SWASH lead investigator Julie Mooney-Somers on this issue here.
7. Be an ally, not a saviour

This was a recurring theme across the spectrum of groups who presented at the conference, whether it be Indigenous LBQ women or trans and gender diverse people – we don’t need saving, we need support.

Too often, delegates heard, service providers would come galloping in on their white horse, martyr complexes aloft, seeking plaudits for top-down solutions. What was actually required was support for community-driven ideas and initiatives.

Presenting Indigenous perspectives, Kirstie Parker called for “good hearts who will stand beside us”, sharing her 10 tips for showing up in solidarity (below), while Dr Vanessa Lee stressed that Indigenous women did not need saving. You can catch our interview with them here.

Rei Alphonso, from the Victorian AIDS Council, urged delegates to free themselves from the tyranny of perfection when it came to seeking allies. Perfect allies, the conference heard, simply don’t exist.

8. Services not known to be accessible are assumed to be inaccessible

All the diversity and inclusion training in the world won’t make a difference if you don’t advertise – proudly – that your service is LBQ and TGD friendly, accessible and safe.

<table>
<thead>
<tr>
<th>Table 43: Ever diagnosed (self-report) with anxiety, depression or other mental health disorder</th>
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<td>2016</td>
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<td>2012</td>
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<td>Yes, over 5 years ago</td>
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<td>Not reported</td>
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<td>Not reported</td>
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<td>Total</td>
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It’s not enough to have an open door, you have to go through it, out into the community, and bring people inside. There are huge barriers to overcome for many people in these groups in accessing health including previous poor experiences. Offering a safe, non-judgmental space of respect, where LBQ and TGD individuals are seen for who they are, goes a long way.

**9. Acknowledge your implicit bias**

No one is free from bias, whether it be about sex, gender, race, sexuality, class, political worldview, taste in music or men. There was much discussion about the overrepresentation of white, middle class women within LBQ community organising; erasure of and discrimination against bisexual women by lesbians and queers and the invisibility of trans and intersex narratives.

When held by those outside the community, particularly health providers, biases (lesbians don’t sleep with men/need Pap smears), can do actual harm.

**Microaggressions** can take many forms, from the binary boxes for sex and marital status on health documents to the way questions are asked in clinical settings (assuming the gender of a partner), the facilities provided (male and female toilets) and the diversity of staff. There are neutral ways to inquire about everything, and there is no excuse for refusing to do so, except implicit bias.

**10. Positive messaging has power**

The greatest moments at #LBQWHC17 were those that captured a community in full flight, whether it was Kirstie Parker’s soaring keynote, Indigenous delegates leading the auditorium in traditional song or the irreverent bass of Smoke Free Still Fierce.

Rather than dwelling on the downsides, delegates revelled in celebrating difference. Any engagement with LBQ women must have this as its starting point.

See here for the rest of our coverage of this event.
Hope and strength as a new generation of Indigenous doctors is welcomed at #AIDAconf2017

The Australian Indigenous Doctors’ Association conference was marked by themes of hope and strength, and provided delegates with a culturally safe space for open discussions about the impact of colonisation and racism within Australian health systems.

Writer and author Karen Wyld reports below that the 20th anniversary conference heard of the benefits of decolonising approaches to health care and wraparound service models that are inclusive of families and communities.

Another key theme was the importance of critical race discourse and cultural safety to improving health and education systems, services and outcomes.

Minister Ken Wyatt also stressed the importance of implementing cultural safety into aged care.

Karen Wyld writes:

The theme of the Australian Indigenous Doctors’ Association (AIDA) conference was very apt. Throughout the many presentations, workshops, cultural and social activities, Family Unity Success was evident, time and again.
AIDA conferences are always well presented, but this year was special. AIDA turned 20 and many members and friends were there to celebrate this milestone.

The conference was held in Pokolbin in NSW’s Hunter Valley, on Wonnarua country.

With a strong line up of speakers and presenters, VIPs included: Dr Jeff McMullen AM, the Hon Ken Wyatt AM MP, Professor Tom Calma AO, Associate Professor Papaarangi Reid and Dr Nathan Joseph (New Zealand), Associate Professor Martina Kamaka (Hawaii), Dr Michael Gannon and Mr Phil Truskett.

**Driving change**

Throughout the conference, other recurring themes emerged, such as: hope, culture, identity, family and community-led solutions.

Whilst many speakers spoke of the need for culturally safe care to improve health outcomes for Indigenous people, ongoing barriers were also named. These included intergenerational trauma, disenfranchised First Peoples in settler colonisation, unacceptable health disparities, racism, racism deniers, and health and education systems that still are not culturally competent.

And, as often occurs when Indigenous peoples gather to talk about issues impacting on communities, strategies were put forward to address the barriers.

Positive ways forward included: decolonising approaches to health care, implementing wraparound service models that are inclusive of families and communities, and critical race discourse.

Another key strategy is creating culturally safe learning environments and ongoing support for Indigenous students/practitioners to successfully grow their career pathways in medicine. This is an area where AIDA demonstrates its leadership to drive change.

With a range of practical and theoretical professional workshops, the Growing Our Fellows session, and presentations on career development, delegates were inspired to further map out their career pathways.

**Strengthening the workforce**

Encouraging Aboriginal and Torres Strait Islander people to grow a career in health starts early.

Donna Murray, CEO of Indigenous Allied Heath Australia (IAHA), spoke of one such program for young people.

In partnership with Aboriginal Medical Services Alliance NT (AMSANT), IAHA manages a Health Academy to support young Indigenous people’s pathway into the health workforce.

Unlike some other Indigenous youth programs, this Academy is not sports-based, and is instead focused on educational achievement.

The Health Academy’s model for workforce development is: support, grow, transform and lead. As Donna Murray says, “With Aboriginal and Torres Strait Islander people leading the programs and solutions, there can only be better outcomes.”

**Centring Cultural Safety**

The need to develop culturally safe systems and services was very much a focus of the AIDA conference, with many solutions put forward to overcome barriers to change.

Systemic racism continues to be a major issue within the health system, and it’s critical to address this to close the gaps for Aboriginal and Torres Strait Islander people.
As **Associate Professor Papaarangi Reid** said: “Failure to respond to racism in the health system cannot be an option.”

Ensuring health systems are free of systemic racism not only increases the likelihood of Aboriginal and Torres Strait Islander people receiving better levels of care, but will build culturally safe work and study environments for the Indigenous health workforce.

The cultural safety panel of distinguished guests provided the opportunity to delve deeper into current flaws within the health system, and to put forward possible solutions.

A conference highlight, this panel consisted of: Associate Professor Gregory Phillips (MC); the Hon Ken Wyatt, Minister for Indigenous Health; Professor Helen Milroy, Commissioner at Australia’s Royal Commission into Institutional Responses to Child Sexual Abuse, AIDA Life Member; Dr Kali Hayward, AIDA President; Ms Theanne Walters, Deputy CEO Australian Medical Council; Professor Brian Kelly, University of Newcastle; and Mr John Batten, Royal Australasian College of Surgeons.

Cultural safety is recognised as a model of health care that is not only anti-racist but addresses the ongoing effects of colonialisation, such as intergenerational trauma, and is based upon analysis of power and issues such as whiteness and institutional racism (read more about the history and evolution of cultural safety in [this previous Croakey post](#)).

During the panel discussion, Professor Helen Milroy stated that: “We need an intergenerational trauma-informed approach.”

Minister Ken Wyatt reminded delegates that aged care also needs to adopt cultural safety models as many Indigenous aged care residents “…are fearful, given memories of institutional life”.

The importance of embedding cultural safety in the curriculum for all medical students was recognised as a contributor to a more competent workforce as well as creating a safer passage for Indigenous students.

As Associate Professor Shannon Springer commented from the audience: “Doctors are not clinically competent unless they are also culturally competent.”

**Two-way health**

Culturally safe health models must include acceptance and incorporation of Indigenous health practices, and an understanding of the importance of family and community.

When speaking of her vital work as a Ngangkari, Josephine Mick said: “We feel a great surge of love for our people and willingly give our treatment.”

This sentiment that was evident in numerous presentations throughout the conference, demonstrating the point-of-difference that Indigenous medical practitioners often bring to their work.
**Broadening the discussion**

Many sessions spoke of the barriers that Indigenous doctors need to constantly navigate.

Terminology such as decolonisation, critical race discourse, social determinants of health, and systemic racism were unpacked.

The need to deconstruct the patriarchy in medicine was also discussed. Dr Ruth Mitchell reminded delegates that surgery was still not a level playing field for women.

And Indigenous women are up against racism and sexism, as they forge a career pathway.

Dr Mitchell said that “as surgeons we cannot fully serve patients unless our workforce reflects the same diversity” within Australian communities.

**Celebrating success**

A gala dinner on the last evening brought AIDA members and friends together, to celebrate the 20th anniversary.

James Wilson Miller welcomed everyone to his country, the lands of the Wonnarua Nation, and read out a moving piece that allowed everyone to ‘see’ the beauty of this country from pre-invasion to now.

Steven Oliver, who MCed the night, also shared some of his poetry and spoken word. With his well-known fusion of humour and sharp social commentary, Mr Oliver received a standing ovation.

Nova Peris OAM, AIDA Patron, shared the stage with Dr Kali Hayward, AIDA President, to present graduates with their well-earned stethoscope.

With 31 graduating Indigenous medical students, the biggest cohort to date, as well as 5 graduating Fellows, this moment was a shining example of AIDA’s success.

Mr Phil Truskett, AIDA Patron and AIDA Life Member, presented the Indigenous Doctor of the Year Award to Associate Professor Kelvin Kong. As Mr Truskett is one of Associate Professor Kong’s earliest mentors, this was a proud moment for both doctors.

Other awards were for Indigenous Student of the Year – Mr Luke Hamlin, and Associate Member of the Year – Professor Annemarie Hennessy.

Twenty years ago, when AIDA started, there were only a few Indigenous doctors. There are now more than 320 Aboriginal and Torres Strait Islander doctors, and over 265 medical students. And every year more Indigenous medical practitioners are breaking barriers to enter new specialisations, to become known as another ‘first’.

With the forging of stronger relationships with the medical colleges and peak bodies, AIDA will continue to provide the high level of leadership, support and mentoring for which it is known.

After immersion in a culturally safe space at the conference, many delegates left with a renewed sense of hope, knowing they had support to grow their careers in medicine.

[https://karenwyld.com/consultancy-services/](https://karenwyld.com/consultancy-services/)

See [here](https://karenwyld.com/consultancy-services/) for the rest of our coverage of this event.
Tweets from a Doctors for the Environment Australia conference

#HealthMatters @WSPublicHealth @h
Acknowledgement of country at #IDEAConf, in Melbourne on traditional land of the Wurundjeri people of the Kulin Nation @DocsEnvAus

#HealthMatters @WSPublicHealth @h
Room filling for @DocsEnvAus #IDEAConf on climate change & health - @mariemcinerney covering for @CroakeyNews with @croakeyblog also on watch
Quoting Ban Ki-moon that climate change is the true existential threat: health profs need to counter half-truths: @DocsEnvAus #IDEAConf

Never been more important to stand up to protect health through care of environment: intro at #IDEAConf from @DocsEnvAus

Braganza: heatwaves biggest killers for extreme weather: seeing massive shift from once every 30 yrs to once a summer #IDEAConf @DocsEnvAus

What can GPs do on climate change? @DrBastianSeidel: ‘connect the dots, be true advocate for yr patient, say when it’s a cc effect’ #IDEAConf

8 reasons to solve climate change, obesity together: @SandroDemaio #IDEAConf

1. Both are tough sells with complex scientific underpinnings.
2. Both face powerful forces.
3. Both about externalities, outcomes of a broken economic model.
4. Shared confounders, determinants
5. Shared opportunities
6. Both running out of time
7. Equity needs to be central imperative
8. Are two sides of the same coin.

‘I talk climate chaos, I don’t talk climate change,” says @doctorbiooz “It’s not going to be beautiful vineyards in north England” #IDEAConf

Medical colleges need to also work closely with other stakeholders in climate change health, incl indigenous people/comm’ties: #IDEAConf
See [here](#) for more about this event.
Unfinished business: Health & other sectors urged to address unmet needs of Stolen Generations

A new report highlighted Australia’s continuing failure to address the needs of the Stolen Generations and the grief, loss and anger that has been passed on as a result to their children and grandchildren.

The Healing Foundation report was launched in Canberra in the leadup to the 20th anniversary of the landmark 1997 Bringing Them Home report, and provides important reading for the health, aged care and social sectors, as well as demanding strong and bipartisan political leadership.

Journalist Melissa Sweet covered the launch of Bringing Them Home: 20 years on: an action plan for healing for the Croakey Conference News Service. She later interviewed Indigenous Health Minister Ken
Wyatt and Labor frontbencher Linda Burney, who said there is cross-party support for the report (watch the interview at the bottom of the post).

Melissa Sweet writes:

Health, aged care and other services must better meet the needs of the Stolen Generations through provision of trauma-informed services and improved training, according to a new report launched to mark the 20th anniversary of the Bringing Them Home report.

The Healing Foundation report also calls for a trauma-informed public policy environment so that policy makers become better informed about the historical and living trauma suffered by Stolen Generations members and their descendants. It says:

Inadequate education about this history is impairing the ability of governments, service providers and Aboriginal and Torres Strait Islander organisations to effectively meet their needs.

Existing training does not support police, welfare services, health and mental health providers and institutions such as aged care facilities to respond effectively to the increasing distress Stolen Generations and their descendants might experience by coming into contact with these services, often agents of harm from their past.

In addition, trauma informed training that is currently available does not cover the trauma experienced by our Stolen Generations members and their families, and often does not come from a cultural perspective.

The report calls for trauma training packages to be designed with Stolen Generations survivors to ensure governments, professionals and services are able to respond effectively and without causing more harm.

It also calls for all levels of government to develop a universal, safe and culturally appropriate scheme for financial redress for the Stolen Generations and their families. It contrasts the Federal Government’s previous refusal to provide a national compensation process for the Stolen Generations with its willingness to lead development of such a scheme for people who were sexually abused while in institutional care.

The report was launched at Parliament House in the lead-up to the 20th anniversary of the tabling in the Australian Parliament of the landmark Bringing Them Home report.

The 1997 report followed a two-year inquiry by the Human Rights and Equal Opportunity Commission documenting horrific stories about the reach and impacts of government policies taking Aboriginal and Torres Strait Islander babies and children from their families, country and cultures (see example below).

The report found that between one in three and one in ten Indigenous children were forcibly removed from their families and communities between 1910 and 1970, and that this involved “both systematic racial discrimination and genocide as defined by international law”. 

The new report, *Bringing Them Home 20 Years on: an action plan for healing* report says most Aboriginal and Torres Strait Islander people have been affected by the Stolen Generations.

“The resulting trauma has been passed down to children and grandchildren, contributing to many of the issues faced in Indigenous communities, including family violence, substance abuse and self harm,” it says.

“Two decades on and the majority of the Bringing Them Home recommendations have not yet been implemented. For many Stolen Generations members, this has created additional trauma and distress.

“Stolen Generations members are aging, and there is an urgent need to ensure they, and their families, don’t face further trauma by a failure to achieve justice in their lifetime.”

**Recommendations for action**

The new report calls for dedicated needs-based funding and for a focus on healing intergenerational trauma backed by proper resourcing.

It notes that the Bringing Them Home counsellor positions originally funded in 1997 are now expected to provide general social and emotional wellbeing services for the whole Aboriginal and Torres Strait Islander community.

“The lack of focus on the specific needs of Stolen Generations members and their families is exacerbated by the large amount of funding for Aboriginal and Torres Strait Islander mental health and social support services now being funneled by the Australian Government’s Indigenous Advancement Strategy (IAS) to non-Indigenous NGOs, and in some cases to church-run organisations,” the report says.

“This is creating barriers for Stolen Generations members and their descendants to access services because in a number of cases the services are provided by the same churches who ran the institutions where the children were forcibly removed and traumatised.”

The report also calls for government reporting processes to specifically include sections on the Stolen Generations, to ensure a focus on their needs and how these are being met.
Powerful launch

The significance of the new report was recognised with both the Prime Minister Malcolm Turnbull and Opposition Leader Bill Shorten attending the launch, as well as many MPs and about 70 members of the Stolen Generations.

Australian National University Professor Mick Dodson, who co-authored the 1997 report with Sir Ronald Wilson, said it was one of the most challenging things he had ever done in his professional life but also one of the most rewarding.

The extent of the horror revealed by the report was “shocking and devastating”, even for an Aboriginal man like himself with connections to this history.

Dodson said he recognised at the Parliament House launch many people who gave evidence to the inquiry 20 years ago, and he urged the audience “let’s not fail them again”.

Professor Steve Larkin, Chair of the Healing Foundation and Pro Vice-Chancellor (Indigenous Education and Research) at University of Newcastle, said the unresolved trauma of the Stolen Generations was affecting current generations.

There was a clear link, he said, “between two decades of inaction and many of the health and social problems in communities today.”

“We can’t afford to fail our stolen generations again,” he said. “We have got to break the trauma cycle, for their sake, for the sake of their families and for the sake of every Australian.”

Mrs Florence Onus, Chair of the Healing Foundation Stolen Generations Reference Committee, who was one of multiple generations in her family to have been removed from kin, land and culture, said it had been “heartbreaking and disappointing” that so few of the 1997 recommendations were implemented.

However, the new report’s launch felt like “a new beginning and an opportunity to address unfinished business”, she said.

Political leadership

In an interview with Croakey after the launch, Minister Ken Wyatt and Labor MP Linda Burney reflected on their shared history – both were present at the 1997 Reconciliation Convention in Melbourne when the Bringing Them Home report was presented.

Wyatt, who last year became the first Indigenous Cabinet Minister in Australia, said it was the responsibility of all governments to address the unmet needs of the Stolen Generations.

He was confident the issues would be addressed, as there was very strong bipartisan support as well as from the Greens, he said.

Burney, the first Indigenous woman elected to the House of Representatives, said: “I think both the Prime Minister and the Leader of the Opposition were very genuine in giving a commitment to look closely and to examine closely and to work together on those recommendations.”
More to watch from the #BTH20 event

In this interview, Professor Ngiare Brown, who was MC at the launch at Parliament House, describes her work with children, young people and trauma. If there is unresolved grief and trauma in the life of an individual, then it is not only their story but a narrative that affects everyone connected to them, she says.

She urged political leaders to engage with the report: “I’d just like to say that Aboriginal and Torres Strait Islander peoples are providing leadership so let’s see our parliamentarians, our politicians and all of the departments match that kind of leadership,” she said.

You can also follow this link to watch the official speeches at the launch from Florence Onus, Professor Mick Dodson, Prime Minister Malcolm Turnbull, and Opposition Leader Bill Shorten.
The future is fast approaching, but are we ready? A LongRead on what AI might hold for rural health

The rapidly advancing field of Artificial Intelligence (AI) is set to shake up the health and healthcare of rural communities, the National Rural Health Conference was told.

The prediction and its accompanying warning – from a leading rural doctor and medical educator, Dr Jenny May – is underscored by a scan of recent medical publications, reports Melissa Sweet.

Melissa Sweet writes:

Not so long ago, a worrying realisation crept up on Dr Jenny May, Director of the University of Newcastle Department of Rural Health.

Perhaps she was failing in her day job – training the doctors, nurses and allied health professionals of the future.

May began questioning whether she and her colleagues were preparing the next generation of health and medical professionals for models of care and service delivery that might not exist in the future.

She subsequently began a journey investigating the burgeoning field of artificial intelligence (AI) and its implications for the future of healthcare. It was somewhat out of her comfort zone, as May describes herself as anything but “a geek”.

May presented her findings to the 14th National Rural Health Conference in Cairns, warning that the rural health sector needs to prepare for seismic changes in how it does business (and her caution no doubt applies more broadly as well).
She painted a picture of a future where intelligent machines have replaced pathologists, oncologists and many other health professionals, and where autonomous vehicles have made large sections of the rural workforce redundant.

It is also quite likely that in this future, she warned, the transformational changes brought by AI and the Fourth Industrial Revolution will exacerbate social, economic and health inequalities.

May’s concerns are underscored by a World Economic Forum assessment of the wide-ranging impacts of the Fourth Industrial Revolution, which is described as “a fusion of technologies that is blurring the lines between the physical, digital, and biological spheres”.

Klaus Schwab, Founder of the World Economic Forum, has foreshadowed an exponential pace of technological change in coming years, writing:

- The possibilities of billions of people connected by mobile devices, with unprecedented processing power, storage capacity, and access to knowledge, are unlimited.
- And these possibilities will be multiplied by emerging technology breakthroughs in fields such as artificial intelligence, robotics, the Internet of Things, autonomous vehicles, 3-D printing, nanotechnology, biotechnology, materials science, energy storage, and quantum computing.”

Schwab says that to date those who have gained the most from such changes have been consumers able to afford and access the digital world, and that there are concerns of the potential for greater inequality to result from disrupted labour markets.

“The largest beneficiaries of innovation tend to be the providers of intellectual and physical capital—the innovators, shareholders, and investors—which explains the rising gap in wealth between those dependent on capital versus labor,” Schwab says.

He adds:

- Technology is therefore one of the main reasons why incomes have stagnated, or even decreased, for a majority of the population in high-income countries: the demand for highly skilled workers has increased while the demand for workers with less education and lower skills has decreased.
- The result is a job market with a strong demand at the high and low ends, but a hollowing out of the middle.”

**Advancing AI**

“Artificial intelligence” is not a new concept, with a recent review of AI in medicine noting that the term was first coined in 1955 to describe “the science and engineering of making intelligent machines”.

However, the review described an increasing application of AI across healthcare in recent years.

It cited wide-ranging examples, including sophisticated robots providing care to frail elderly in Japan, emotionally sensitive avatars helping people with paranoid hallucinations learn to moderate their behaviour, and the use of algorithms and knowledge management to boost discoveries in genetics and molecular medicine.

Meanwhile, doctors from New York City reported a small study last month in the journal Stroke, showing that a smartphone app using AI was effective in helping stroke survivors to use anticoagulation medication appropriately.

The randomised controlled trial of 28 patients reported that 100 percent of the group using the app took their medication as directed, compared with 50 percent of the control group.
The study was sponsored by a US-based company, AiCure. Its app visually identifies individual patients and confirms their ingestion of medication.

The publication follows a growth in the number of start-ups exploring the use of AI in healthcare, with one industry analyst predicting that by 2025 “AI systems could be involved in everything from population health management, to digital avatars capable of answering specific patient queries.”

Meanwhile, researchers from Imperial College London in England and the Massachusetts Institute of Technology in the US recently cautioned that while AI could identify patterns and trends in routinely captured clinical data that yielded useful clinical insights, it also risked leading to over-diagnosis and unnecessary interventions.

Commenting on a study about AI being used to identify patterns in the clinical data of patients with atrial fibrillation and atrial flutter, the authors said AI brought the risk of generating “a variety of signals with little to no clinical relevance”.

Their article, published this month in the journal, Critical Care Medicine, defined overdiagnosis as the detection of disease that, if it had remained undetected, would not have affected a person’s life.

The downsides of overdiagnosis included patient anxiety, harm from further testing and unnecessary treatment, and the opportunity cost of wasted time on the part of both patient and provider, and healthcare resources that could be better used to treat or prevent genuine illness. The researchers said:

**The use of AI may well contribute to this problem by discovering patterns undetected by the human mind that are not actually causing problems and never will.**

**Clinically meaningful advances in this field will be an iterative process, where new algorithms are developed and systematically tested in real clinical settings for relevance against hard clinical endpoints. Only those that demonstrate value should be refined and improved before consideration for systematic bedside implementation.**

These authors also noted that despite several decades of research and hype, the AI field had failed to deliver on its promises of automated and improved disease detection, more effective monitoring and efficiency boosts in workflow – a caution also echoed by a CSIRO scientist in this article in The Conversation late last year.

However, algorithmic advances have started to trickle into areas such as radiology and pathology, the researchers said.

**Future fast approaching**

May predicts that the use of AI in healthcare is set to advance rapidly in coming years, with smart phones being used for X-rays, pathology tests and genomic profiling.

“If you are a pathologist, I think you need to be having some career counselling about now, because many of the things that you would have considered bread and butter are probably yesterday,” she told Croakey.

“I think there will be very few things that in the future that computers with the use of AI can’t do.

“I was very surprised to find just how much technology using AI is already out there, and is already part of many other peoples’ daily clinical work flow.”

Examples cited by May included the use of sensors in the homes of elderly people to assess gait length and alert health professionals when this was noted to shorten, which is predictive of the likelihood of falls.
She also said that IBM’s **Watson for Oncology** (read more [here](#)), which can crunch lab tests, read doctors’ notes and provide highly validated treatment recommendations, raises questions about the future of oncologists, as well as other health professionals.

May also described another IBM algorithm called **Medical Sieve**, which aims to build a next generation “cognitive assistant” with analytical, reasoning capabilities and a wide range of clinical knowledge, to help clinical decision making in radiology and cardiology.

Last year, **Atomwise**, which uses supercomputers that root out therapies from a database of molecular structures, launched a virtual search for safe, existing medicines that could be redesigned to treat the Ebola virus, May said.

They found two drugs predicted by the company’s AI technology that may significantly reduce Ebola infectivity. This analysis, which typically would have taken months or years, was completed in less than one day, according to May.

Developments in AI outside of healthcare also will have significant implications for health.

The advent of autonomous vehicles – which the recent World Congress of Public Health in Melbourne was told had the potential to bring public health gains by reducing traffic accidents – could add to rural unemployment, May said.

She noted that a significant proportion of rural workers are employed driving cars, buses, trucks and harvesters, for example.

“We are going to lose a swathe of these jobs,” she said. “That’s of great concern; we need to be preparing for this sort of structural reform. This is a whole-of-community revolution.”

May said the potential for AI to reduce the number of health professionals needed in rural communities also could contribute to wider job and population losses.

“In some of our smaller communities, the health service is the major employer,” she said.

She also warned that the AI revolution had the potential to exacerbate health inequalities because it was likely to be unevenly available in an environment where developers were likely to focus on profits rather than providing equitable service to communities.

“Similar to the institution of other market-based approaches, it may be of benefit to individuals but not to communities as a whole,” she said.

May is also concerned about inability of current structures to adequately regulate AI developments, especially as it is likely that vast amounts of personal health data will be held offshore.

### NBN failings

But one of the major barriers to equitable access was the uneven access to high quality NBN, she said.

May has recently returned from a year working in rural British Columbia in Canada where a town of 6,000 people had unlimited high speed broadband.
“The Canadian Government had invested significant amounts in high speed broadband, which made all these technologies possible,” she said.

*Ubiquitous high speed broadband is a necessity. I’m not interested in an answer that it’s too expensive or we can’t do it.*

As just one example of how uneven NBN access is already affecting healthcare, May said she finds it almost impossible to place students on even short-term clinical placement in rural areas without good broadband access. They just won’t go there.

At the moment, she says broadband is patchy in northwest NSW and through to the coast, although some towns have excellent access via the NBN.

“For anybody who would like to see regional rural and remote communities go ahead with the potential that they have, I believe that we need the highest possible speed broadband,” she said.

Contrary to some suggestions that rural people do not need quite the same bandwidth or speed as city people, the reverse was true, May said.

*If we look at agriculture or health or education, I would have thought the need was on steroids.*

By the time the next national rural health conference is held, in Hobart in 2019, May hopes that rural communities and the health sector have progressed much further in their understanding of the likely impacts of AI and the Fourth Industrial Revolution.

“The question is,” she said, “is there a way we can adequately prepare for it?”

**Watch Croakey’s interview with Dr Jenny May**

[Watch Video]

See [here](#) for the rest of our coverage of this event.
Indigenous Data Sovereignty: More than scholarship, it’s a movement

There’s growing acknowledgement that Aboriginal and Torres Strait Islander people and communities have been “researched to death” since the early days of colonisation, yet given little control over or access to data that is collected.

The emerging Indigenous data sovereignty movement asserts that Indigenous peoples across the globe have inherent and inalienable rights relating to the collection, ownership and application of data about them and their lands and lives.

In the #LongRead below, Goori researcher, writer and journalist Jack Latimore reports for the Croakey Conference News Service from a symposium on Indigenous data sovereignty held in Melbourne, which wants to build momentum in Australia, including through a national network like the Maori-led Te Mana Raraunga. You can follow him on Twitter at @LatimoreJack.

The symposium was hosted by the University of Melbourne in partnership with the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). Croakey’s coverage was sponsored by the Lowitja Institute, Australia’s national institute for Aboriginal and Torres Strait Islander health research.
Jack Latimore reports:

Indigenous data sovereignty may provide Aboriginal and Torres Strait Islander people with valuable resources to overcome Indigenous disadvantage and realise true self-determination and empowerment, a symposium heard.

The Indigenous Data Sovereignty symposium at the University of Melbourne brought together representatives of data initiatives from Indigenous communities across Australia with researchers, Indigenous health advocates, government advisors and other data practitioners.

As well as hearing from leading Indigenous Data Sovereignty policy and research “warriors” from Australia and Aotearoa/New Zealand, the two-day event heard from community led projects from the Kimberley in Western Australia to Bourke and Brewarrina in New South Wales that are “doing Indigenous data sovereignty already”.

These local examples of project development and governance – and the data yielded within communities – highlighted big gaps in Indigenous data and data sovereignty but also showcased ways to tackle concerns about potential exploitation.

Leading Indigenous academic Professor Marcia Langton, one of the convenors, said data sovereignty concerns the ability and capacity of Indigenous people to locally manage their data “with respect to ownership, access, consent, collection, analysis and reporting”.

She said there is significant evidence – recognised by the Prime Minister in his 2017 Closing the Gap report – that addressing complex issues of disadvantage for Indigenous Australians “requires the existence of data that is relevant and of high quality”.

“However, the lack of reliable and consistent disaggregated data for Indigenous Australians is striking, resulting in the paucity of evidence-based Indigenous policy-making,” she said.

“Data are not neutral statistics”

Keynote speaker Maggie Walter, a Palawa woman from north eastern Tasmania and Professor of Sociology and Pro Vice-Chancellor of Aboriginal Research and Leadership at the University of Tasmania, told participants that the symposium was important to move the conversation on Indigenous data sovereignty forward in Australia.

“It is our data, our way and our right,” she said.

“I’m so thrilled to hear from the community groups here,” Walter said. “You guys are doing Indigenous data sovereignty already. It is happening already. And it is really heart-warming to see that it is happening.”

However, she said there was also bad news implicit in those initiatives, many of which had arisen because of poor data governance by non-Indigenous organisations previously.

“As Indigenous peoples, we have long been the subject of data collections,” Walter said.

In Australia, she said that has been mostly done by the Australian Bureau of Statistics, the Census, the National Aboriginal and Torres Strait Islander Social Survey (NATSISS), hospitals, schools, legal systems, universities and all the data that is being collected now through the Federal Government’s Indigenous Advancement Strategy programs.

And the private sector is also involved.
“The intent in the way that those data have been gathered and analysed over the years has varied from the benign to the malignant, but what they all have in common is that they have all very rarely been collected by us or for us,” she said.

“And – just as critically – data are not neutral statistics. They are inherently human artefacts and they overtly display the cultural, social and political power imbalance between those collecting and analysing those data, and those of us who are their data subjects.”

In light of these concerns, symposium organisers and participants are aiming to:

1. develop a nationwide network to empower Indigenous organisations and communities to take advantage of developments in data science and maximise the use of their data resources for community benefit
2. increase awareness of the importance of Indigenous data sovereignty for local Indigenous communities, researchers, government and other related stakeholders
3. provide information on custodianship, management of, and reporting and presentation of data, including models of monitoring and evaluation
4. outline specific strategies and approaches to make better use of data that Indigenous people already have undisputed sovereignty (for example, the information held by the Indigenous land councils, medical services, legal services etc)
5. provide information on custodianship, reporting and presentation of data.

Data sovereignty cannot be “top-down”

Keynote speakers at the event included Andrew Sporle, a researcher in Indigenous statistics at the University of Auckland, and Dr Tahu Kukutai, Professor of Demography at the University of Waikato.

Both are founding members of the Maori data sovereignty network, Te Mana Raraunga, a model of Indigenous data governance and advocacy that the convenors of the symposium aim to develop in Australia.

“What we are trying to do in Aotearoa with Te Mana Raraunga is carve out an ultimate vision around our data and our sovereignty and our future and what that might actually look like,” Kukutai said. “It’s about the right of Maori to access, to use, to have governance, to have control over Maori data.”

In defining Maori data, Kukutai said there is “a whole multitude of ways of thinking about data”. It involves data sets and infrastructure, she said, but data can also be cultural artefacts or even the location of significant sites. The real challenge is to be able to capture data in a way that is meaningful and that enables communities to be part of it, she said.

“It’s never going to work as a top-down academic endeavour,” she said. “We absolutely need to work beside our communities in order to do this appropriately.”

That need for community-led data governance and ownership was a common theme emerging from presentations and panel discussions at the symposium, as was the view of data as a tool for realising self-determining aspirations.

With ever-growing cloud-based storage and sharing of data by business, academic institutions, non-government services and government agencies, Kakutai warned that sharing of Indigenous data can be seen as “a new land grab”.

Croakey conference highlights 2017 | 80
If there are processes and mechanisms around data protection or data governance, they are focused on individual protection and individual rights rather than collective or community ones and therefore deliver no defined benefit to community, she said.

“At the moment, some of the terminology that I’m hearing is about Indigenous data to be shared, to be discovered, to be opened up, but to be controlled or owned by non-Indigenous governance, non-Indigenous entities, non-Indigenous researchers,” she said.

“There may be rhetoric around benefit to communities, but there’s actually no clear and transparent line of accountability back to communities.”

In such a space, Indigenous communities have opportunities to develop processes, principles, structures, networks and enabling mechanisms to be able to be self-determining in this space, she said.

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**Bourke: “telling a young person’s story”**

Skye Bullen, the Community Data Manager from the Maranguka Justice Reinvestment Project in Bourke told the symposium how the Maranguka project uses a community-based participatory research approach to reduce the high rate of Aboriginal children and young people’s offending, reoffending and incarceration in adult prison and youth detention.

“Local knowledge in Bourke is a key contributor to making a concrete and constructive difference,” she said.

Bullen said the Bourke Tribal Council has full control of the data that is collected under the Growing Our Kids Up Safe, Smart and Strong strategy that guides the project, the first major justice reinvestment initiative in Australia.

Further vital information is sourced from other community groups such as the Maranguka Youth Advisory Council, The Journey to Healing Women’s Group, and the Men of Bourke.

“These groups actively participate in the data collection process and the results are openly available to them for things such as policy articulation, planning, monitoring and evaluation,” she said.

Bullen said that the Maranguka project not only ensured that Aboriginal people in Bourke have the right to maintain, control and protect the data that is collected about them, but also govern the direction of the project.

“The first stages of the project focused on building trust between community members and service providers,” she said.

“The data that we collected looked to tell a story about a young Aboriginal person’s journey through the criminal justice system in Bourke. We looked at things such as offending, diversion, bail, sentencing, days and times of offences, and reoffending rates.”

The project also collected data about early life, education, employment, housing, child safety, and health care, including mental health and drug and alcohol issues, she said.
All that information was then fed back to the Bourke Tribal Council which set out an agenda for the Maranguka project, with working groups adopting a ‘test and trial’ approach to determine which activities best drive progress towards the project’s goals and targets.

“Using our shared measurement system, we’re now going to closely monitor our performance and track the activities and adapt our approach as necessary,” she said.

Bullen believes that the project can drive sustained change in Bourke, but she said success involves the community having the power to lead and define outcomes.

The project is focused on giving community members a platform to define their needs, and for working group members to refine their work based on the information collected. Local organisations must work collaboratively with the community to ensure goals are achieved, she said.

An online dashboard is currently being developed, to augment other ways that the project reports via social media, quarterly results and a newsletter, to make sure it continuously reports transparent, relevant and real-time data back to the working groups and community.

“The value that we find in this collaborative approach is the effective mapping of service sector supply and demand, with subsequent adaptation of services,” she said. “Most importantly change is in the hands of the Bourke community. This allows us to identify and celebrate our achievements.”

Among those early achievements have been a reduction in police cautions, warnings and move-ons, as well as in driving offences, domestic violence reoffending, and a significant increase in education engagement for the majority of at risk young people.

“Services in Bourke really benefit from this data being shared with them. It ensures that we’re unlocking our future together,” she said.

**Algabonyah Data Unit: tracking progress, performance**

Participants also heard about the Algabonyah Data Unit established last year (as part of the Empowered Communities initiative) by the Kaiela Institute in Victoria’s Goulburn Murray region, traditional land of the Yorta Yorta people.

Kaiela Institute executive chairman Paul Briggs said one of its major pieces of work will be to deliver a comprehensive annual regional report card to the Algabonyah Community Cabinet, with the first due to be published in December.

The report card will track progress for the local Yorta Yorta community against key indicators and community priorities and the performance of government-funded organisations, to hold the region accountable to the prosperity measures the community is seeking.

“The purpose of the scorecard is to establish what the regional priorities are and to align regional investment and regional resources to those priorities,” Briggs said.

Briggs said the project was not just focused on Federal Government Indigenous funding but all public and private investment in the region.

“We’re talking about the way the region drives its prosperity. We’re moving from measuring our deficits into measurements around investment, productivity and prosperity,” he said.

“We think that move will also inform the way in which we address Aboriginal health services, legal services, child care, and housing and whether the resources that we’re investing in terms of people and dollars are giving us the returns that we want.”
Briggs said a 2009 Access Economics assessment of Shepparton that was commissioned by the Kaiela Institute discovered that if Indigenous economic parity with non-Indigenous people was achieved, productivity of the town would increase by $61 million.

That could be a powerful motivator for non-Indigenous people in the region, he said:

If there’s nothing else driving non-Indigenous people to look in our direction and to seek to be a part of the answers to the challenges, there’s actually some cash in it."

You’ll sell more cars, you’ll sell more houses, you’ll sell more pizzas. And that productivity assessment isn’t across Yorta Yorta country, it’s just Shepparton itself.”

Briggs said that data had stimulated the business sector and local government to engage more enthusiastically with the Algabonyah Community Cabinet.

“Our region has a GDP of about $8 billion and integrating Indigenous prosperity measures into regional planning should reflect both our contribution to that GDP, as well as what we receive from it,” he said.

Raelene Nixon, a community engagement officer with the Algabonya Data Unit, told the symposium the Yorta Yorta community began pursuing data sovereignty as far back as 1988 as a way to disentangle itself from pervasive welfare dependent structures.

It became involved in data processes again in 2006 amid concerns the Australian Bureau of Statistics had under-counted the region’s Aboriginal people for that year’s national census.

Working with the University of Melbourne’s School of Rural Health, the community employed 12 local Aboriginal members to carry out new research, which found that the ABS initial count fell 30 percent short of the region’s actual Aboriginal population.

Again in 2009 the Algabonyah Community Cabinet analysed local data sets to ask what worked in Closing the Gap in Shepparton and the Murray Goulburn region.

Workshops were held involving Aboriginal community members, representatives from all levels of government, non-government organisations, academics and members of the non-Indigenous local community, Nixon said.

“We identified data needs for our community, identified the gaps, and with that information started to ask what community data governance structure would look like. At the time 98 percent of our community were saying that it was important that we have a regional data governance body, though were split on what that might look like,” she said.

The consultations finally led to the creation of the Algabonyah Data Unit.

Its role is to resource the Yorta Yorta community with knowledge in a sophisticated way, and to protect local Aboriginal people from unethical research, said Karyn Ferguson, also a community engagement officer with the unit.
It will also assist in the sustainability of Yorta Yorta culture and identity, and ensure that the local voice is injected into research in all its stages.

“We want to measure the things that are important to us, to identify what our priorities are. We want to measure the resource allocation and investment into our region, IAS (Indigenous Advancement Scheme) funding for example, and also what the state government resourcing is around infrastructure, like building new hospitals.”

Ferguson said some of early benefits coming from the work of the unit is that the data now reflects community boundaries and imposes “an Aboriginal community lens”.

“So, we’re talking about Yorta Yorta people on Yorta Yorta country, as opposed to local government boundaries,” she said.

“Also, while we do have the quantitative data and access to those data sets, we’ll provide the Aboriginal community lens that goes over the interpretation and analysis to ensure that our voice is across data and research at all times.”

**Yawuru Knowledge and Wellbeing: “I designed it”**

The symposium also heard about the Yawuru Knowledge and Wellbeing Project from the Kimberley region of Western Australia, another initiative to emerge from cultural flaws in ABS national census data.

**Eunice Yu** of the Kimberley Institute, which set up the project, said a number of accountability issues emerged in 2010 for the local Yawuru people over funding for an Indigenous language agreement signed with the Western Australian Government and the Shire of Broome.

“We needed to work out where to get appropriate data from in regard to how many Yawuru people were out there. The Census data didn’t break down into local language groups,” she said.

Three months out from the 2011 Census, Yu was employed to run a specific Yawuru demographic survey, which she says finally yielded accurate numbers about both the number of Yawuru people and other Aboriginal people living in the Broome region.

“We needed to establish a baseline of information in relation to what Native Title was going to bring to us, and what benefits the Yawuru people would be able to demonstrate as a result of the investment and change in the landscape that we were about to embark on,” she said.

“Further to that we wanted to show that what was important to Yawuru people would actually be able to be demonstrated across not only our community but across the nation.”

Like the Algabonyah community-led data initiative, Yawuru people were employed as the research team. The research process started with interviewing Elders to identify potential data indicators that were important to them.

As over 100 indicators were developed, the project began to evolve into what might represent wellbeing for Yawuru and, in 2015, the **Yawuru wellbeing survey** was conducted.

Project collaborator **Mandy Yap**, a research fellow at the Crawford School of Public Policy at the Australian National University who works in partnership with the Yawuru community in Broome, said she knew the research had integrity when she watched a Yawuru reference committee member participate in the survey.

“He was answering the questions with his wife, and because it is quite a long survey – we have a hundred questions in there – it takes about an hour and a bit. And he did it in half an hour because he wanted a race between the husband and wife.
“And the wife said, ‘Well how did you do it so quickly? It took me an hour and a half!’ And he said, ‘Well it is because I have designed the survey. I designed it, so I knew what I was going to say.’ From my perspective as a researcher, sitting there and hearing that from him, that was the tick I needed to know that the research reflected his values and what his thoughts were.”

Ngemba Data Research Hub: “when people don’t have a voice, they grieve”

For Jason Ford, a Ngemba man and cultural consultant with Dhirragggal Solutions, the team managing the Ngemba Data Research Hub project in central New South Wales, Indigenous data sovereignty goes hand in hand with nation building.

Having worked in the past with the New South Wales Department of Primary Industries and as an Aboriginal Liaison Officer in bio-security, Ford said he realised the significance of data after hearing colleagues talk about collecting information on threatened animal groups, such as koalas.

“I was really interested because they were talking about collecting this data so that this species could coexist with the movement of contemporary Australia,” he said.

“I started thinking about my own people, the Ngemba people, and I said, well they can collect information about the koala on where he is, what his habitat is, population demographics. Yet for my Ngemba people, I couldn’t find any information about my mob.”

Ford said the project was driven by community concerns about significant Ngemba cultural erasure as a result of the data collection and governance by non-Indigenous institutions such as the ABS, and state, federal and local government bodies, but also Indigenous organisations such as the NSW Aboriginal Land Council, the Native Title Services Corporation and even the region’s own Indigenous Murdi Paaki Regional Assembly.

IDS community Ngemba Jason Ford

There is no quality assurance to current models of governance that control Ngemba data, Ford said. As a result, Ngemba nation boundaries began disappearing off of new maps of traditional nation boundaries in the region.

Ford said even the Ngemba name was often not appropriately attributed to the nation’s significant cultural sites, such as the local heritage fish traps.

“There’s been no consultation with the Ngemba Elders and they’re really concerned with this type of behaviour, about having no jurisdiction around data, and how things appear to be headed, without the Ngemba having a voice,” he said.

“When people don’t have a voice they grieve, they grieve.

“And it’s very concerning when you see our people, when they grieve, they start to do things which contribute to poor health, because they’re not being listened to.”

See links to other community data initiatives:


You can access a free download of Indigenous Data Sovereignty: Towards an Agenda, edited by symposium keynote speaker Professor Tahu Kukutai and John Taylor, Emeritus Professor at the Centre for Aboriginal Economic Policy Research at The Australian National University. Many of the symposium presenters have also contributed articles to the publication.
You can also view a selection of tweets from the symposium at the @WePublicHealth archive: Week Oct 7

The symposium was convened by: Professor Marcia Langton, Associate Provost, Chair of Australian Indigenous Studies, University of Melbourne; Professor Shaun Ewen, Pro-Vice-Chancellor (Indigenous), Director, Melbourne Poche Centre of Indigenous Health, University of Melbourne; Professor Janet McCalman and Dr Kristen Smith, Melbourne School of Population and Global Health; Dr Nikki Moodie, Melbourne Centre for the Study of Higher Education; and Dr Len Smith, Australian National University.

Jack Latimore writes for Koori Mail and Guardian Australia. He is the daily editor of IndigenousX. His work has previously appeared in Overland, Inside Story, Crikey, NITV, SBS, & the ABC.

See here for more information.
Why the NDIS was a hot topic at #LivingOurWay – and stacks more conference news

Important concerns about the potential impacts of the NDIS upon Aboriginal and Torres Strait Islander people emerged at the #LivingOurWay conference.

Karen Wyld writes:

Attendees at the recent First Peoples Disability Network Australia (FPDN) conference shared a united message: nothing about us, without us. This sat comfortably alongside the official conference theme – Living Our Way.

The Living Our Way conference was held in Wagga Wagga, on Wiradjuri country, between 23 and 25 May 2017. It was attended by Aboriginal and/or Torres Strait Islander people with lived experience of disability, carers, people working in the disability sector, and other interested persons.

The conference was sponsored by the Australian Centre for Disability Law.

With FPDN hosting, and a predominantly First Peoples audience of attendees and guest speakers, the message of nothing about us, without us was strongly embraced throughout the three days.

Key Themes

Other messages emerged throughout the conference, all contributing to an understanding of what it means to be Living Our Way for First Peoples living with a disability. Not surprisingly, the National Disability Insurance Scheme (NDIS) was a much-discussed topic.
Listening to conference presenters and audience questions, the key themes included:

- Using our way (i.e. by and for First People living with disability) no one gets left behind
- A combination of evidence-based and knowledge-based (culture, community, lived experience) is a stronger approach
- The benefits of using a social model of disability
- Positioning disability as a stand-alone Closing the Gap target
- Intersectionality of First Peoples living with disability
- Government, National Disability Insurance Agency (NDIA) and mainstream disability services need to engage more; to listen and respect First Peoples living with disability and peak bodies/advocates
- Resources need to be given directly to Aboriginal and Torres Strait Islander controlled services/peak bodies
- Potential opportunities through NDIS – such as employment, increased services and consumer-control
- Concerns about NDIS – including eligibility, unclear processes, poor communication, and capacity to deliver locally-relevant culturally-appropriate services
- Expected barriers of accessing NDIS for people living in rural/remote communities – such as lack of equitable access and limited choice.

Setting the scene

On the morning of Tuesday 23 May, attendees and guest speakers were welcomed by Aunty Clorine Lyons. June Riemer, Deputy CEO FPDN, then opened the conference. First speaker was Damian Griffis, CEO FPDN.

To acknowledge the 20th anniversary of the Bringing Them Home Report, Griffis led a minute’s silence for the many people affected by the forced removal of children.

For more information on #BTH20, see the Healing Foundation’s Bringing Them Home – heal our past, build our future.

Damian Griffis, a Worimi man with decades of experience working within the disability sector, set the scene for the next three days.

He spoke of how First Peoples have always been inclusive and caring of family and community. As is often said, there is no word in First Nations’ languages for disability. Griffis also referred to archaeological evidence that backs up First Peoples’ oral histories of communities caring for people who have a disability.

He stressed that disability is not a health issue, which is why FPDN uses a social model of disability. Griffis spoke of the barriers and social determinants that can impact on Aboriginal and/or Torres Strait Islander people who are living with disability.

Clear links between social determinants (i.e. poverty and nutrition, access to housing) and historical drivers (i.e. colonisation, key policy eras, institutional racism) can often be explaining factors for the high prevalence of disability amongst First Peoples in Australia.

Griffis also proposed solutions, such as the urgency for disability to be a stand-alone target in the Council of Australian Governments’ (COAG) Closing the Gap strategy.

The way in which resources are allocated also needs addressing. There is ample evidence that positive outcomes occur when First Peoples are resourced to lead and deliver their own initiatives.
With an estimated nine percent of NDIS consumers being Aboriginal and/or Torres Strait Islander people, there is no better time than now to discuss resources, services and opportunities. Potentially, the NDIS could result in more services and resources, and a growth in Aboriginal and Torres Strait Islander employment.

Griffis highlighted two areas of employment disparities that need to be addressed: people living with disability, and carers. Friends and family members often go beyond the role of carers; providing a level of care similar to service providers but in an unpaid capacity. Such carers need to be better supported, and paid as disability workers. Providing opportunities for Aboriginal and/or Torres Strait Islander people living with disability to secure accessible and stable employment is also essential.

To better position the First Peoples disability sector, FPDN will be launching a 10-point plan later this year, putting forward a strong position on why First Peoples need to lead and control their own markets (i.e. disability services, resources and workforce).

**Keynote speech – and calls for action**

The next speaker on day one was Alastair McEwin, Disability Discrimination Commissioner, Australian Human Rights Commission.

McEwin commenced this role in July 2016, bringing with him extensive experience in law, education, arts, and disability.

He has an impressive array of past roles, including coordinator of the World Federation of the Deaf Expert Group on Human Rights, CEO of People with Disability Australia, and Manager of the Australian Centre for Disability Law.

McEwin’s respectful approach, and understanding of the disability sector as a person with lived experience, was evident throughout his speech. And he made a few strong calls for action.

Taking every opportunity possible to advocate and steer change is a part of McEwin’s strategy.

For example, he says that he will often ask members of Parliament how many people with disability their departments employ. By doing this he is able to challenge them to think, and then possibly re-think their preceptions, which can lead to change.

McEwin has a few goals in his position as Disability Discrimination Commissioner, such as working collaboratively with June Oscar, Aboriginal and Torres Strait Islander Social Justice Commissioner, Australian Human Rights Commission. Oscar only commenced in April 2017, so they have not yet had time to sit down to talk.

In a short interview later that day, McEwin elaborated further on some of the points raised in his keynote speech. He was joined by Scott Avery, FPDN Policy and Research Director, who asked several questions that elicited poignant responses from the Disability Discrimination Officer.

The conference program was well-constructed, with all presenters offering a lot of information, useful tips, and positivity.
**Day one**

The keynote speech was followed by Tania McInnes, Director of Hard to Reach, NDIA Scheme Practice Branch (Northern Territory), who explained the approach that her team has taken in developing NDIS resources and rolling out the program in NT.

She went into depth to show their 3-tier Engagement Strategy, which is inclusive of community and family. McInnes, an Aboriginal woman in a leadership role, proudly talked about the high Aboriginal and Torres Strait Islander employment rate within their branch.

In this session, there was considerable comments from the floor in regards to NDIS and First Peoples. Many people had concerns about people being overlooked during the roll out stage, and choice of services not being adequate in rural/remote regions.

Next up was Paul Calcott, National Operations Manager, FPDN. A Wiradjuri man with lived experience of a disability, he uses art in many of his projects, including in the development of the Proper Way planning book, which is supported by an interactive resource booklet and film. These resources will be launched later this year, in time to support First Peoples to prepare for the NDIS.

Using a narrative approach, Proper Way will assist people to identify what supports they will need to live their way, and to plan their ideal NDIS package. It is hoped that culturally-appropriate and easy-to-use resources such as Proper Way will enable more Aboriginal and Torres Strait Islander people to receive services that best fit their aspirations and needs.

It was good to see local media cover the conference. WIN News Riverland interviewed FPDN employees, guest speakers and attendees, to use on their televised news program later that day.

In the afternoon, attendees split into three groups to attend Breakout Sessions. Targeted resources were the key theme of Annamarie Reyes’ session. Reyes works with My Choice Matters, who have developed a range of resources for multicultural communities. They intend to develop specific resources for Aboriginal and Torres Strait Islander peoples.

As in previous sessions, concerns about NDIS were raised, such as: equitable choice of services, appropriate resources for First Peoples need to be developed by First Peoples, and accessibility of information.

There were concerns about the NDIS’s lean towards online, which could create accessibility issues for Aboriginal and Torres Strait Islander peoples who have no/limited access to phones and computers. Added to inadequate internet access in remote regions, this will be a huge barrier for many.

Christine Regan, New South Wales Ombudsman, ran through some of the training packages and videos that her team uses in upskilling people to know their rights. She used elements of the disability rights training programs, so this session was very interactive.

The last session of the day was outstanding. Dianne Brooks, NSW Manager, FPDN, used real life scenarios to unpack the NDIS principles. Brooks, a Yorta Yorta woman with extensive experience as both a carer and professional in the disability sector, talked about how good planning will enable people to get the most out of NDIS.

She was joined by a work colleague, via Skype. Tanya Lewis, FPDN, spoke to the group from her bed.

Due to lack of adequate services, Lewis had been confined to a nursing home after a stroke when she was younger. Lewis was the first Aboriginal person to receive a NDIS package, which enabled her to leave a nursing home and back to family.
Lewis had a strong message to share – just give it (NDIS) a go. And state what you need from the scheme, learn how NDIS works, and make it work for you. This session was one of the standouts from the conference, with a very positive message to end the day on.

**Day two**

Scott Avery, Policy and Research Director, FPDN, was the first speaker on day two. A Worimi man and doctoral candidate with an ability for making stats and facts tell strong stories, Avery quickly had everyone’s attention.

As with Damian Griffis’s session the previous day, Avery talked about why FPDN uses a social model of disability.

Avery explained the co-design research model that he uses in his work.

He also talked about his recent intersectionality research, and how it relates to Aboriginal and Torres Strait Islander people living with a disability.

Using an evidence-based approach, Avery has been able to better advocate, as well as map emerging trends. He sees research as another avenue where First Peoples living with a disability can be heard. His approaches are honest, and people-led.

Avery read out a few alarming stats. For example: 45 percent of Aboriginal and Torres Strait Islander people have some form of disability. 7.7 percent have a severe and profound disability (34,000 people). This is 2.1 times higher than other Australians (using an aged adjusted ratio).

However, the Australian Government does not have any stand-alone First Peoples disability departments or strategies, and lacks culturally competent models of funding and service provision.

Several people in the room acknowledged Avery for his research work, which has been valuable in their daily work. And Damian Griffis, FPDN CEO, remarked: “We don’t own that data. We want everyone to use it, to speak up.”

Next up was a late addition to the program. Regan Jewsen, NSW Department of Industry, and Harriet Jobson, NSW Department of Aboriginal Affairs, spoke of a new, collaborative program. Disability Sector Scale Up is an innovative approach by the NSW Government, to help business and community become NDIS-ready. This collaboration, with an allocated $4.5 million, will support employment and start-ups in the disability sector.

Once again, attendees raised concerns about having access to culturally-appropriate services, especially in rural/remote regions, and the potential loss of grass-roots services that communities currently have good relationships with.

Regan Jewsen, a Sydney-based Aboriginal woman working in government, acknowledged that she does not have all the solutions, but trusts that each community will.

Both Jewsen and Jobson were supportive of seeing Aboriginal and Torres Strait Islander community-led initiatives, and encouraged people to talk to them.

Non-NSW attendees expressed hope that other states and territories will implement similar programs, and funding, to help people transition to services under the NDIS.

Next session was presented by Dean Bright, Senior Manager Murrumbidgee, Intereach Planning. Social Futures, a NSW NDIS partner, has sub-contracted Intereach.
Bright spoke of Intereach’s approach, to enable them to reach the 4,000 people eligible for NDIS in their service-region. Basically, if people don’t speak with Intereach, then they won’t get an NDIS package.

To be able to reach people, and support them to get the right NDIS services for their needs, Intereach knows they need to build the right team. They are currently recruiting, and hope to attract Aboriginal and Torres Strait Islander employees.

Next up was Rochelle Pitt and Melicha Woodcock, presenting on the far-north QLD Cultural Holiday Leave for Aboriginal and Torres Strait Islander people on dialysis.

Rochelle Pitt, a Wirri/Butchella/Kalkaddon woman, is a renal nurse at **Apunipima** Cape York Health Council, and Kidney Health Australia Ambassador. Melicha Woodcock, a Yungabarra/South Sea Islander descendent, is a carer and disability advocate from Cairns. She is currently working with **Synapse’s QLD NDIS Participant Readiness Project**.

They talked about the many barriers that Aboriginal and Torres Strait Islander people on dialysis have if they need to attend community/cultural activities, including Sorry Business, going back to Country, or visiting family.

To highlight some of these barriers, and to explain the initiative they’ve implemented, they used a case study. Uncle Willy Kabay had not been home for 13 years, having moved to access regular dialysis treatment. Uncle Willy joined in the discussion via Skype.

This story had a happy ending, with Woodcock opening her home for Uncle Willy, after a massive team effort to get him to Cairns for two-weeks of Cultural Holiday Leave. And Uncle Willy is now planning his next trip, which he’ll squeeze in between his volunteering at a local men’s group.

Pitt then spoke about new technology that could potentially enable more Aboriginal and Torres Strait Islander people to go home to country, community and family. Or to access dialysis from their homes, instead of frequent trips to hospitals. The video she showed, of very slim-line, easy-to-used dialysis machines, was inspiring. If funded, this new technology will be a lifesaver for many First Peoples.

Last session for day two was Tom Powell, Wiradjuri man, from **Red Dust Healing**. He developed this program to support social emotional healing for Aboriginal and Torres Strait Islander people. It’s had a big impact on supporting men and boys.

Powell took attendees through the reasoning behind the program, and demonstrated the key activities.

A video presentation showed some more benefits of the program, as well as testimonials from past participants.

**Day three**

After an enjoyable conference dinner, with entertainment by Col Hardy and his band, the first session on the final day was Suzanne Donnelly from Positive Partnerships, speaking about their work with Autism Spectrum Australia.

**Positive Partnerships** is a national project, funded by the Australian Government, that works with schools to support children with autism and their families.

They have a broad range of **resources and online supports**, DVDs, online courses, interactive tools, and fact sheets. Also available are resources developed specifically for Aboriginal and Torres Strait Islander families.
Emma Bedwin and Jenny Beath, Community Engagement Coordinators, Department of Fair Trading NSW, then covered the NDIS and people’s rights. Bedwin outlined the ‘business’ side of setting up NDIS contracts, including the complaints process.

With approximately 400 accounts of consumers’ issues during the NDIS rollout, it’s important that people know their rights. Protecting personal information is essential, including not allowing service providers access to log on details. Being safe online and over the phone was a key message, as there have already been instances of scam-callers. Becoming more aware of NDIS processes, consumer rights, complaints processes, and where to get support, will enable people to get the services they need.

This was a very informative session, with a few cautionary tales and strong messages on how to be safe and empowered during the transitioning to NDIS.

Jake Briggs, FPDN, talked about NDIS Coordination Workforce. Briggs, a Kamillaroi/Wonnarua man with professional and lived experience of disability, explained how he viewed the conference theme of Living Our Way. And reminded everyone of FPDN’s strength of being by and for First Peoples living with disability.

Briggs provided some excellent tips on getting the most from NDIS and service providers. And stressed that individuals are now in control, with the ability to choose what supports they need and what services to engage.

As mentioned in previous sessions, Briggs sees ways that the NDIS can potentially strengthen the Aboriginal and Torres Strait Islander disability sector and workforce.

Briggs also spoke briefly about innovative designs in purpose-built housing, before being joined on stage for the final session.

Ben Riemer, FPDN, joined Jake Briggs to talk about their work with Koori Courts. Approached by judges who saw a need for better support of Aboriginal and Torres Strait Islander people with disability presenting to Court, FPDN stepped in. The program currently operates in Parramatta, but needs to be expanded. This work is not funded, which is a barrier to expansion.

Briggs estimates that 2 out of 5 young Aboriginal and/or Torres Strait Islander people going to Koori Court have a disability. Mostly intellectual or cognitive, and lacking support services. Briggs and Riemer can link people to supports, to stop them falling deeper between the cracks.

This program is built on strong engagement principles, with Briggs and Riemer working with Elders, young people and community.

As the last session wrapped up, June Riemer, Deputy CEO, spoke highly of this engagement work. She also recognised the need to mentor and build the future leaders within the First Peoples disability sector.

**Closing on a positive note**

The last session transitioned into a conference wrap-up. June Riemer asked FPDN staff to come forward, as she thanked them for their contributions in ensuring the conference was a success.

June thanked the conference sponsors, Australian Centre for Disability Law, who have been supportive of FPDN in many ways.

Uncle Lester Bostock was acknowledged for his decades of leadership, research and advocacy in the First Peoples disability sector.

The First Peoples Disability Network’s Living Our Way conference ended on a positive note, with attendees looking back on past achievements, while being prepared to move forward together.

The message throughout the Conference, and beyond, is powerful: nothing about us, without us.
Further information and contacts
To find out more about the sessions held at the Living Our Way conference, contact First Peoples Disability Network Australia on (02) 8399 0882 or email enquiries@fpdn.org.au

And to stay up to date, follow FPDN on:

Twitter @FPDNAus

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Website www.fpdn.org.au

The Living Our Way conference was kindly sponsored by the Australian Centre for Disability Law.

Media releases and articles in relation to the Living Our Way conference were posted by:

First Peoples Disability Network Australia

National Aboriginal Community Controlled Health Organisation


https://karenwyld.com/consultancy-services/

See here for the rest of our coverage of this event.
Indigenous allied health professionals are leading change

Karen Wyld writes:

Indigenous Allied Health Australia’s recent conference provided professional development for delegates, and opportunities to connect with others working in health, education and policy.

For Aboriginal and Torres Strait Islander delegates, it also provided a culturally safe space for celebrating achievements and connecting with Indigenous leaders in health, enabling renewed energy.

As health and wellbeing do not exist in a vacuum, broader social and political events were woven through presentations and in informal conversations.

Topics such as cultural safety in health, community-led solutions, strength-based approaches, generational leadership, and growing the future allied health workforce were a welcome antithesis to the many challenges that workers in health deal with on a daily basis.
And, of course, some of those challenges were discussed by presenters and delegates.

These included policy constructed by non-Indigenous people who lack on-the-ground knowledge, resulting in poor Closing the Gap outcomes and continued systemic inequity.

Also discussed was the urgent need to change systems that cause harm, such as what emerged through the recent Royal Commission into the protection and Detention of Children in the Northern Territory, so young people are better supported to achieve their aspirations.

Also clear was the harsh reality that achieving human rights for First Peoples is still a long way off when calls for a Constitutionally-recognised voice are ignored.

**Cultural responsiveness**

Culturally-grounded models of working were discussed throughout the conference, with a focus on cultural safety and cultural responsiveness.

Most workers in the Australian health sector would by now be familiar with cultural safety.

Numerous Aboriginal and Torres Strait Islander health organisations have adopted cultural safety as a standard, such as Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) and the Australian Indigenous Doctors Association (AIDA).

IAHA uses a cultural responsiveness model, and has recently published Cultural Responsiveness in Action: An IAHA Framework.

Ms Faye McMillian, outgoing IAHA Chair, states on the IAHA website that: “This capability framework provides guidance around what we need to know, be and do in order to be culturally responsive.”

The IAHA Cultural Responsiveness Framework consists of six key capabilities that detail ways of knowing, being and doing: respect for centrality of culture, self-awareness, proactivity, inclusive engagement, leadership, responsibility and accountability.

There are many similarities between cultural safety and cultural responsiveness, such as: providing guidelines to health practitioners to improve their capabilities; putting the onus on change onto non-Indigenous systems and employees; debunking the myth that culture is the ‘problem’, as opposed to racism and systemic inequity; and progressing the conversations beyond cultural awareness or sensitivity, to create real change.

**Decolonising health**

On the second day of the conference, Associate Professor Gregory Phillips, presented the morning keynote, titled Accreditation for Addressing Racism, which outlined a sound model for applied cultural safety in Australia.

Phillips spoke of the lingering health effects of colonisation, and the impact of racism on health and wellbeing. He reminded delegates that First Peoples’ cultures are not the problem, and that is the responsibility of non-Indigenous health practitioners to remove racism from the health system.

Using a decolonisation process might be the key to achieving this. Decolonising health means confronting the values and mindset of whiteness, which currently maintains the unfair status quo in Australia.
Like other speakers, Phillips pointed to factors that can drive change in health and wellbeing for Aboriginal and Torres Strait Islander people – embedding cultural safety standards in health and within national law, decolonising practices on a personal and systemic basis, and understanding the essential role of Indigenous knowledge in the delivery of services.

Phillips reaffirmed that Indigenous knowledge is the intellectual property of First Peoples. And, because Aboriginal and Torres Strait Islander peoples are not a homogenous population, he noted that Indigenous knowledge differs across place, context, history, languages, cultures, and spiritualities.

Cultural knowledge is one of the unique points-of-value that Aboriginal and Torres Strait Islander allied health professionals bring to their workplaces.

His presentation reflected key messages that had been evident from day one of the conference. MC Adele Cox opened the conference with a reminder that cultural safety results in more accessible health care for Aboriginal and Torres Strait Islander people.

In her keynote speech, June Oscar AO, Aboriginal and Torres Strait Islander Social Justice Commissioner, expressed the belief that Indigenous allied health professionals will lead the way for sustainable health for Aboriginal and Torres Strait Islander people.

And she urged delegates to never underestimate the value of their work, referring to the IAHA Cultural Responsiveness Framework as an example of best practice.

**Closing the Gap**

Phillips also said in his keynote, “If you want to Close the Gap, you have to deal with racism”, and stated that cultural safety is not a one-time achievement, but a process of continual learning.

As building on past failures is an element of continual learning, it’s positive to see that this may have been taken on board in the current Closing the Gap Refresh.

On the final afternoon of the conference, Sam Jeffries, Special Advisor for Regional Governance Indigenous Affairs, presented the Department of Prime Minister and Cabinet’s current *Closing the Gap: Refresh*.

Next year, it will be ten years since the Council of Australian Governments first committed to the Closing the Gap strategy. Since then, only one of the seven targets is on track (increased completion of year 12 education).

Closing the Gap was developed with almost no input from Aboriginal and Torres Strait Islander people and communities. The Government states that the Refresh will involve a community engagement process.

A proposed prosperity framework has been developed ahead of this engagement process, with four focus areas being: economic, individual, community, and environment.
Social determinants of health

Throughout the two days, speakers presented numerous examples of the social determinants of health for Indigenous people, including from a lived experience perspective.

When introducing acclaimed musician Archie Roach as the last keynote speaker, IAHA Patron Professor Tom Calma made the connection between social determinants and good health and wellbeing.

This theme was evident in the very personal stories told in the closing address.

Roach presented *Tackling Smoking: A holistic approach to our life journey*. Combining story with song, Roach took us through the key moments of his life.

He framed the impacts of being a member of the Stolen Generations with social and emotional wellbeing, and health issues. From smoking, alcohol and drugs, poor nutrition, to family violence, poverty and homelessness, Roach provided an honest reflection of how both social determinants of health and lifestyle choices can contribute to chronic health, disease, and poor social emotional wellbeing.

Archie Roach’s story also detailed the tools that can heal: belonging, culture, justice, family, and acceptance.

Care, cultures, connect

Before the conference, IAHA CEO Donna Murray said participants could expect a diverse and lively range of discussions, and that: “We hope everyone will come away from the Conference feeling stronger and with some practical strengths-based tools and actions to support them in their role and their communities.”

It was evident from feedback that this was indeed the case.

Some sessions took people out of their comfort zones, by asking non-Indigenous delegates to reflect on the values they bring to their work, and encouraging them to trust that Aboriginal and Torres Strait Islander people can lead change.
Non-Indigenous health professionals were asked to instead take a lead role in addressing racism within health systems.

Such conversations can be confronting, but they are vital to moving forward together, as personal reflection is a core element of cultural safety in health.

The conference centred the core role of allied health workers in improving health outcomes for Aboriginal and Torres Strait Islander people and communities.

As June Oscar AO said, allied health workers are the glue in the health system. And, as demonstrated by many of the Aboriginal and Torres Strait Islander speakers, Indigenous allied health workers bring with them lived experiences, community connections, Indigenous knowledge, and a passion for contributing to equitable and culturally safe health care.

The 2017 IAHA conference provided delegates with reinvigorated passion, and ideas and tools to take back to their workplaces, so they can continue to deliver health services grounded in care, cultures and connection.

https://karenwyld.com/consultancy-services/

See here for the rest of our coverage of this event.
Health equity, prevention and better integration of services: key priorities from the ALP Health Summit

Thanks to Croakey readers and contributors who supported our #HealthMatters crowdfunding campaign, journalist Marie McInerney was able to attend the ALP Health Summit in Canberra to provide this detailed report of the topics discussed.

**Marie McInerney writes:**

Labor’s national health policy summit put health equity, prevention, and better integration of fragmented services at the heart of its health policy development in the lead-up to the next election.

The Federal Opposition, buoyed by the importance of health at the 2016 election, invited more than 150 health experts from different fields to ‘round table’ discussions on many of Australia’s most pressing health issues, and responded with its own big numbers.

Opposition Leader Bill Shorten officially opened and closed proceedings and sat in on a number of sessions.

Key members of his Shadow Cabinet were also on hand — Catherine King (Health and Medicare), Julie Collins (Mental Health and Ageing), Jenny Macklin (Families and Social Services), Mark Butler (Climate
Change and Energy), Stephen Jones (Regional Services, Territories and Local Government) and Warren Snowdon (Indigenous Health) – along with a dozen or so other MPs.

There were no big announcements or new directions set, although a communiqué will be issued in coming days.

However, many of those attending said the event signalled that Labor was making a priority of health and that its show of Shadow Cabinet strength and the issues on the agenda recognised – at least tacitly – the need for whole-of-government or Health in All Policies (HiAP) approaches.

Participants told Croakey there were benefits in having a big crowd of people committed to improving health in the same room, sharing an agenda with people outside their own ‘silos’ and reitering key issues and messages with politicians and advisors that they often don’t get to reach.

Those messages also went out more widely, with the hashtag #alphealthsummit trending top on Twitter nationally through the day.

“People in health might have heard much of what was discussed before, but not all the politicians and advisors necessarily have, and there’s some energy just in getting everyone together,” said Jennifer Doggett, chair of the Australian Health Care Reform Alliance (AHCRA) (and a Croakey editor).

It was all of course limited by the nature of the event, which packed eight sessions on big picture topics – from prevention, hospitals, mental health, innovation and more (see the full list of topics in this earlier Croakey story) – into less than six hours.

At the final plenary, session chairs had just a few minutes to give a wrap of the complex discussions they had led. But even that sent a strong policy signal when Mental Health Australia CEO Frank Quinlan observed that, in the time each chair spoke, someone in Australia had attempted suicide.

His summary of the mental health session was both poignant and a warning on the big gap between intent and political reality, saying mental health advocates had come to the summit with an agreed agenda, “no jockeying”, but still waiting for action on a reform process that had taken years.

Hunger for a long-term vision

Opening the summit, Shorten told delegates the Opposition wanted to build an “irresistible coalition for reform and change” and prepare a health policy ahead of the next election that answers “the hunger for a long-term vision”.

“We want to move beyond the boom and bust in healthcare policy in the recent past, the uncertainty created by deep cuts or sudden swerves in policy or funding.” (You can watch his speech on his Facebook page).

Bill Shorten said it was not good enough that Australia allocates less than 2 cents in every health dollar to prevention measures, and he stressed the importance of reducing fragmentation in the system and improving continuity of care.

He spoke to the hearts of most delegates there that properly funded health care should be seen as an investment, not a cost.
Shorten talked about the health issues that most people bring to him at his ‘town hall’ meetings – anxiety about ice addiction, mental health and suicide, dementia (issues “not related to postcodes”, he noted).

And he asked the sector for help in addressing obesity – bringing to mind comments from former Labor Health Minister Nicola Roxon in 2013 on her frustration at the lack of a “clear message” from health advocates on obesity prevention, versus the strong messages on tobacco.

But the media conference held by Shorten, King and Collins for the press gallery in the midst of the summit pointed to the difficulty in putting substantial health reform on the agenda. It elicited just one telling question on health (as was reflected in this write-up):

**JOURNALIST:** Mr Shorten you ran a fairly negative campaign on health at the election, do you rule out using things like text messages and cold phone calls in the next campaign, are you going to just run a positive health campaign?

**Postcode-determined health**

In fact, there were many stories to be told from the summit.

Mark Butler, a former Mental Health Minister, talked about the Better Access program that provides Medicare rebates for people seeing psychologists. Its first evaluation found that the richest 20 percent of Australians received three times more of those Medicare dollars than the poorest 20 percent.

“That’s not uncommon in these demand driven programs that rely very heavily on a whole range of supply factors but also rely on where the medical workforce is: the further you lived from the GPO the less likely you were to receive a Better Access visit, and the less likely it would be with a clinical psychologist,” he said.

That “postcode-determined health” was also graphically illustrated by ConNetica Director John Mendoza. He said that Blacktown in Sydney’s west, with a population of 330,000 plus people, has not one private psychiatrist versus the north shore suburb of Mosman, whose 32,500 residents have access to 100 local psychiatrists – 1,000 times better access.

Mendoza urged Labor to put such data into the public domain and, when next in government, to set up a Health in All Policies subcommittee in Cabinet to match the power and purpose of the Expenditure Review Committee.

Another delegate urged governments of all stripes to stop designing health systems for “white, male 50-year-olds” and to make them “for the person with kidney disease in the Torres Strait” – “the 50-year-old will be fine”, she said.

Rosemary Calder, Director of the Australian Health Policy Collaboration, hailed the work of acclaimed urban designer Gil Penalosa, who transformed Bogota with his 8-80 litmus test: creating cities that are good for both 8 and 80-year-olds.

One delegate quoted the New Zealand Mental Health Commissioner as saying the markers for a healthy life include “a house, a job and a date on Saturday night”. “We don’t measure any of them,” he said.

Lack of data was a big issue across sessions – as always, but exacerbated by the Coalition de-funding a number of data collection, analysis and research organisations. Priorities that came up included measuring program impact and workforce issues, but also to have health data connected to other policy domains.

Amid many concerns about issues for rural and remote Australia, one advocate called on Labor to make sure all policies are “rural proofed”, saying that there were often unintended consequences to good policies when they did not test for quality and equity in more remote communities.
Others talked about their concerns at being left off the agenda (rare disease care, broader role for pharmacists, oral health, rehabilitation under the NDIS), being left out of reform discussions (nurses) or “ambushed” in a rapidly evolving reform process (aged care, pathology).

And Suicide Prevention Australia’s Sue Murray called for a national strategy on suicide prevention, providing a unified approach that also addresses children and young people (not as “little adults), saying many services currently were operating in a “vacuum”.

**Walking the talk in Indigenous health**

National Aboriginal Community Controlled Health Organisation (NACCHO) chair Matthew Cooke put Labor on notice to address racism in the health system, which Lowitja Institute CEO Romlie Mokak said was the “burning issue” in Indigenous health.

Cooke said the problem is not just in the way Indigenous people are treated in the system but also in how governments and their agencies exclude Indigenous organisations that should be involved “at every level of decision-making”.

He said NACCHO members had been “spearheading” self-determination for more than 40 years – a principle now being adopted by non-Indigenous people wanting to make community decisions about their health care and about health services and systems in communities.

“But Labor forgot us with Medicare Locals and the Liberals forgot us with the PHN (Primary Health Networks) transition… We were left out in the makeup of governance structures, clinical councils and community networks.

“We face a lot of arrogance, a lot of racism in the health system,” he said.

Cooke said a statement this week by Indigenous Health Minister Ken Wyatt, calling on PHNs to work with ACCOs was “very welcome”.

Wyatt has also reached out to Labor to get more traction on Indigenous health, Shadow Indigenous Health Minister Warren Snowden told Croakey. He said Wyatt initiated regular fortnightly meetings with him and Labor Shadow Assistant Minister for Indigenous Affairs Senator Pat Dodson during parliamentary sitting sessions.

Snowden said there would be differences in policies and approaches but, “all credit to Ken”, it was an effort to work collaboratively.

Indigenous health was a big focus in many of the sessions and raised by Shorten, but Labor’s vows to work in partnership with Aboriginal and Torres Strait Islander people and recognise Indigenous health leadership would have perhaps resonated even more if an Indigenous health expert had been among the session chairs at the summit.

**Climate change “no brainers”**

While the impact of climate change on health was not explicitly raised in the session summaries, Mark Butler talked about the “often enormous synergies” between good health policy and climate change/urban planning policies when he co-chaired the session on health inequalities and whole of government challenges.

And the reverse is also true, he said, talking about the recent heatwave in western Sydney that had broken records. Yet, he had read that morning that the New South Wales Planning Department had just lost all its health care resources.
“That lack of integration of health care and planning, I thought we’d resolved ten years ago,” he said, adding that urban design for western Sydney to avoid the heat island effects that were going to be more prevalent “is a no brainer”.

Butler mentioned he had given up eating farmed meat ten years ago as a commitment to addressing climate change, and this also brought health benefits.

Citing the work of the late Professor Tony McMichael, he said there were similar benefits in driving down carbon emissions from cars (people walk more) and shutting down coal stations (good for air quality).

“We need to think about these things in more holistic way, not just thinking as policy makers in a health care area but policy makers who are committed to social justice and sustainability,” he said.

**Where to from here?**

Catherine King’s office said the next step will be to drill down deeper into priority areas raised at the summit, though there’s no detail yet on how that will happen. One of the specific ideas raised was for a national data summit on population health and accountability of health funding.

It will, of course, depend on how big a reform agenda Labor wants to develop and which of the competing vested interests it will need or want to take on to really address structural barriers – doctors, hospitals, states, the pharmaceutical industry, the private health sector and whether it’s up to a fight against the food and alcohol industries and “nanny state” critics on prevention.

After the summit, Public Health Association of Australia CEO Michael Moore told Croakey there’s no point expecting immediate policy change, but he said consultations by King three years ago had led to “probably the best we’ve seen on preventive health” from Labor at the last election.

He also expects to see the ideas that Labor is now canvassing filtering into parliamentary enquiries and reports.

Still, Jennifer Doggett warns that history should keep us cautious, pointing to this section from the 2009 National Health and Hospitals Reform Commission report.

> **The case for health reform is compelling.** The health of our people is critical to our national economy, our national security and, arguably, our national identity. Our own health and the health of our families are key determinants of our wellbeing. Health is one of the most important issues for the Australian people, and it is an issue upon which they rightly expect strong leadership from governments. While the Australian health system has many strengths, it is a system under growing pressure, particularly as the health needs of our population change. We face significant challenges, including large increases in demand for and expenditure on health care, unacceptable inequities in health outcomes and access to services, growing concerns about safety and quality, workforce shortages, and inefficiency. Further, we have a fragmented health system with a complex division of funding responsibilities and performance accountabilities between different levels of government. It is ill-equipped to respond to these challenges. We believe we can do better, and now is the time to start.

She said: “Eight years on and we’re still saying the same things!”

* Thanks to Jennifer Doggett for her help in covering this event.

See [here](#) for the rest of our coverage of this event.