Marie McInerney reported on the AH&MRC Tackling Tobacco and Chronic Conditions Conference 2016 in Sydney, from May 3-4, for the Croakey Conference News Service.

Croakey is a social journalism project for public health based in Australia.
http://croakey.org
On the power of community controlled services for Indigenous health

Marie McInerney writes:

Aboriginal community controlled health services (ACCHSs) deliver a much wider impact than is usually understood even by their supporters, according to an evidence review conducted by the Aboriginal Health and Medical Research Council of New South Wales.

The review found that ACCHSs not only improve the health of Indigenous people, but also the performance of the broader health system, and offer not just a best practice model but one of the few examples of comprehensive primary health care in Australia.

The findings of the review, Aboriginal communities improving Aboriginal health, were outlined in the opening session of the AH&MRC’s Tackling Tobacco and Chronic Conditions conference in Sydney.
AH&MRC Public Health Officer Dr Megan Campbell, co-author of the report, said ACCHSs deliver a broad and integrated range of services, including clinical care, population health programs, onsite pharmaceutical dispensing, specialist services, family violence and child protection programs, community support, accommodation for homeless people, transport and outreach services.

“ACCHSs are one of the few settings (in the Australian health system) where comprehensive primary health care exists,” she found.

It was a timely message, coming as Indigenous health groups braced for more bad news in the Federal Budget.

Conference presenter, Vicki Wade, the Heart Foundation’s Leader on Aboriginal Health and a member of the Closing the Gap Steering Committee, welcomed the report, saying it was an “important” rebuke to the “piecemeal offerings” of government funding that have caused so much uncertainty for ACCHs and their workforces.

It was particularly important given how much funding was lost by ACCHSs to non-Indigenous organisations under the Indigenous Advancement Strategy over the past two years, she said.

Speaking to Croakey after the presentation, Wade said it was the first time she had heard evidence about potential benefits from ACCHSs for the broader health system.

In the absence of similar research in Australia, she was struck also by two studies the report cited from Canada. One found that communities who transitioned from government control to local First Nations community control of health services experienced a 30 per cent reduction in hospitalisation rates. The other found that widely varying suicide rates among Aboriginal communities in British Columbia were strongly associated with the level of community control.

See this Periscope interview with Wade, where she expands on these issues and previews her presentation to the conference on rheumatic heart disease.
### Improving the wider system

Campbell told the conference that ACCHSs helped improve the broader system through partnerships with other health professionals and organisations and through informing better health policy.

While noting that there was little in the published literature on the contributions that ACCHSs make, she said there was evidence that their primary health care model contributes to improved health outcomes for Aboriginal people.

One 2008 study found a remote Northern Territory community served only by an ACCHS had lower all-cause mortality, lower cardiovascular mortality, lower prevalence of diabetes and lower presence of other cardiovascular risk factors compared to Aboriginal people elsewhere in the NT.

The authors saw this as mostly related to the “outstation lifestyle” of the community but also in the way ACCHS responded to that lifestyle through outreach and flexible services.

The report also found that ACCHSs address other social determinants of health directly, including by being the largest employer of Aboriginal people in the country.

![Diagram of ACCHS contributions to health](image)

#### Community control matters for health promotion

The conference heard that community control is also delivering promising results in a small pre-pilot of a culturally adapted version of the New South Wales Government’s Go4Fun for Aboriginal communities.

Health clinician and researcher Nicole Turner, who was also the conference MC, and Lily Henderson, from the NSW Office of Preventive Health, were cautious about the results of the secondary prevention program for primary school kids, given only 55 children and their families were involved.

But they said the program, which took a whole family based approach, had seen the hours of physical activity undertaken each week improve two or three times more than in the mainstream program and reduction of sweet drinks consumption of almost double the mainstream rate.
Key to its success was having Aboriginal facilitators; this not only provided local employment but gave children and their family support from local people they knew and trusted. Changes had also been made to content and language of the program and the way it was delivered, including references to bush tucker, that gave it a ‘cultural identity’.

Turner said her take-home messages were:

“It’s very important to have Aboriginal people from the community knowing the community to deliver these programs, with other health professionals by the side. Also don’t be afraid to say this is a very good mainstream program but it’s just not quite culturally appropriate, there are a few things we need to adapt.”

The program will now be rolled out in another series of pilots, in partnership with more Aboriginal health organisations to extend its reach and test its effectiveness.

A significant anniversary

The opening session of the conference also marked the AH&MRC’s recent 30th anniversary, with CEO Sandra Bailey showing a commemorative video on the development of ACCHs since the nation’s first Aboriginal Medical Centre was set up in Redfern in 1971.

The roll call of AH&MRC champions over those decades have included Professor Marcia Langton, Professor Gary Foley and Roberta Sykes, along with former New South Wales Governor Professor Marie Bashir, once a senior psychiatrist to the Aboriginal Medical Service, and former Deputy Premier Dr Andrew Refshauge, who worked at the Redfern Medical Service too.

Uncle Allen Madden also delivered a poignant welcome to country on behalf of the Gadigal people, saying he was unable to do so in Language because ‘our mob was flogged if we did’.
NATSISS findings

Other important research was also released in the lead-up to the conference, including the latest National Aboriginal and Torres Strait Islander Social Survey (NATSISS).

This is conducted every six years by the Australian Bureau of Statistics and arises from one of the recommendations of the Royal Commission into Aboriginal Deaths in Custody.

NATSISS is the most comprehensive survey about Aboriginal and Torres Strait Islander people, bringing together a broad range of information that explores cultural identity, social networks, housing, health, employment and education, crime and justice experiences and general life satisfaction in the Indigenous population.

This latest survey sounds alarm bells about continuing health and social disparities for Indigenous people in Australia, particularly related to tobacco use and chronic conditions, but also highlights significant gains in education and health and the important role of family, culture and country.

Check out this short animated video released by the ABS to highlight this year’s key findings.

NATSISS champion Professor Tom Calma, head of the Tackling Indigenous Smoking initiative, said the survey has now accumulated 20 years of detailed data to guide research, policy and practice.

“This survey is not just about Aboriginal and Torres Strait Islander people, it’s for us. We need this information to make sure that we are getting things right – we need to feel confident that our issues are accurately reflected in government policies, programs and services,” he said in a statement.

More reports from Twitter

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On the power of community controlled services for Indigenous health

#AHMRC16

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

On the power of community controlled services for Indigenous health  

#AHMRC16
You can track Croakey's coverage of the conference here.

On the power of community controlled services for Indigenous health #AHMRC16

Sarah Agius @agiusj - 2h
#AHMRC16 heading to one of the most best conferences around on Tackling Tobacco and chronic disease.

Marie McInerney @mariemcinerney - 9h
Delegates ready to roll: David Kennedy (L), Awabakul (Newcastle), James Sheather from Armajun (Inverell) #AHMRC16
On the power of community controlled services for Indigenous health

#AHMRC16

Croakey

“Conference News Service”
You can track Croakey’s coverage of the conference [here](#).

On the power of community controlled services for Indigenous health

#AHMRC16
Facebook – a powerful tool for health promotion in Koori communities

Marie McInerney writes:

“It’s like word of mouth or the Koori Grapevine, but on steroids!”

That is the verdict from James Sheather from the Armajun Aboriginal Health Service in northern New South Wales on the role of Facebook in health promotion for Aboriginal and Torres Strait Islander people.

He was speaking at a session on social media on the opening day of the Tackling Tobacco and Chronic Conditions conference.

There was an immediate example at the conference, as the Tharawal Aboriginal Corporation, with AH&MRC support, had just launched a series of 15-second video clips on its Facebook page.

They are part of a targeted social media campaign for young Aboriginal people to prevent the uptake of smoking, which is still the most preventable cause of early mortality and ill health in Aboriginal people.

“We launched it yesterday and we’ve already had a 5,000 reach for the clip,” said Dolie Ufi. Another had notched up 1,000 views, she said.

Young people shape anti-smoking messages

As part of the Youth Film Tobacco Action Project, the mini clips have been developed in consultation with about 13 young Aboriginal people – some were smokers, some had quit, others had never smoked.

Their feedback shaped the content of the clips – which don’t even touch on the adverse health impacts of smoking, but rather the cost of cigarettes and how it stops smokers from buying or enjoying other things.
“Playing with smokes can leave you broke,” was the punch line for one. It pointed out that smoking could cost more than an expensive smart phone, and the Facebook post featuring it also included a link to this online calculator to see how much someone can save by giving up smoking.

Key to their impact, they believe, is the input of young people about content and that they star local people too.

The clips will, said Jasmine Sarin from AH&MRC’s Tobacco Resistance and Control Program, become part of saturation social media campaign, also featuring Twitter.

“You know those really annoying ads you get on your Facebook page?” she told delegates. “That will be us!”

The conference also saw some great clips and promotions from the READY (as in: Really Evaluate and Decide Yourself Make Ourselves Better) MOB Tackling Smoking and Healthy Lifestyles team from the Galambila, Durri and Werrin Aboriginal Medical Services at Coffs Harbour, Kempsey and Port Macquarie. (See photos and tweets at the bottom of this post and watch the clip below).

Unique app in development

And there was news about the development of the Can’t Even Quit app, being managed by the George Institute for Global Health.

Project manager Lachlan Wright said the “Aboriginal specific app” has been designed by Aboriginal people who are current or ex smokers and he thinks it’s like nothing else on the market.

It can be downloaded on cheap mobile phones and has a huge range of different motivational messages which have been adapted for Aboriginal people from Cancer Council Victoria messages. “I’ve been testing it for three months and I’ve never got the same one twice,” he said.

But it’s number one difference, he says, is its My Challenges function, which allows the user to put a whole series of challenges to family and friends, from just delaying the first cigarette a day, to not smoking at work, through to quitting altogether.
Wright says that taps into how smoking is such a “communal thing” in Aboriginal and Torres Strait Islander communities.

“You’re not going to get rid of it by focusing on the individual,” he said. “You’ve got to focus on the family group, the household, the extended mob. That’s what we think is going to be different with this app to any other app that’s out there.”

The comprehensive 2014/15 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) found significant progress in reducing Indigenous smoking rates, although these remain much higher than for non-Indigenous populations.

Rates of daily smoking among Indigenous people were down to 39 per cent from 45 per cent in 2008 and 49 per cent in 2002. About six in 10 (60 per cent) were living in a household in which there was at least one daily smoker in 2014–15, down from 67.5 per cent in 2008 – but still worryingly high rates.

Big funding cuts and changing government policies have had an impact, and the head of the Tackling Indigenous Smoking initiative Professor Tom Calma has conceded Australia won’t meet its target to halve 2008 Indigenous smoking levels by 2018.

**Social media for social change**

Still, James Sheather is a big believer in the power of social media to bring about social change or support.

He told Croakey he was already confident that Facebook would be the key to connecting with Aboriginal people in the area when his organisation began to step up its online presence this year.

But even he was blown away to get more than 10,000 hits on a post that aimed to raise money for a funeral following a suicide in the area.

Fundraising efforts that included a special touch football event organised within a week went on to raise more than $6,000 for the family – a big achievement in an area with roughly 2,000 Aboriginal people in the community.

“It was unbelievable, it all just took off, and showed us how the community wanted to be involved and how to best connect with them,” he told Croakey.

He told a panel discussion at the conference that Armajun’s board had been hesitant about engaging too heavily in social media, concerned about the potential for negative responses.

But they began to swing around when they saw that staffers were directly boosting attendance numbers when they used their personal Facebook account to promote events.

Asked about negative social media experiences, he said trouble loomed once when the organisation posted a vacancy for Aboriginal traineeships, which attracted complaints about “why aren’t these jobs for everybody” from one non-Aboriginal woman.

“The best thing,” Sheather said, “is everyone got on there and told her why. She got a bit of education from her friends and the community. It sorted itself out.”
Photos and tweets

Marie McInerney @mariemcinerney · 2h
Hearing about quit smoking app being developed for indigenous smokers
cantevenquit.org.au #AHMRC16

Facebook – a powerful tool for health promotion in Koori communities
#AHMRC16

Tharawal Aboriginal Corporation Airds
Yesterday at 16:03 ·
Smoking comes with a cost.
Head to: http://www.quitnow.gov.au/.../public.../Content/online-calculator
Calculate how much you can $SAVE on gradually giving up the cigarettes.
For more information please call Tharawal Aboriginal Corporation Airds on:
(02) 4626 4637.
Take that first step.

She can’t afford to shop
because she smokes ...
You can track Croakey's coverage of the conference here.

Facebook – a powerful tool for health promotion in Koori communities

#AHMRC16
Marie McInerney writes:

Not too many years ago, Eileen Byers was overweight, drank more than she should, smoked, and suffered deep anxiety.

Last year, however, she ran the 42-kilometre New York Marathon, part of a select team of Indigenous athletes trained for the event by former Olympian Robert De Castella and team coach Mick Rees.

“Twelve months ago she told me all the things she couldn’t do,” Rees told Croakey. “Now she’s a superwoman.”

Byers, a Bundjalung/Wakka Wakka woman from Casino in northern New South Wales, described her life-changing journey at this week’s Aboriginal Health and Medical Research Council conference in Sydney, “Tackling Tobacco and Chronic Conditions”.
The presentation earned her a standing ovation from delegates, whose ranks she joined earlier this year when she was appointed as an Aboriginal health worker at the Walgett Aboriginal Medical Service, 600 kilometres from home and her first job since she was 18.

A little nervous at the conference, the 31-year-old let her inspiring slideshow do most of the talking but she gave more details in this post, published at the ABC as part of a series about her preparation for New York. In it she said:

“Back in January 2012 I was unfit, overweight, hadn’t worked since I was 18, I’d been a mum since I was 15 and I was struggling with alcohol abuse and low self esteem. I was so so timid I was too scared to apply for jobs or do any courses to improve my situation.

Then I met my current partner in March 2012 and I got a glimpse that I could make a change. He was a healthy role model and so when [he] got a job working on an outback station, I made a decision to show him I could also be healthy. The kids were all at school and I had loads of free time so I took myself off to the gym for my own personal makeover. I was 89 kilos and surprised myself when I dropped 18 kilos in just 16 weeks.

But then when he returned we decided to have baby and within weeks I was pregnant.

By the time I had our baby I’d crept up to 103 kilos.”

Changing lives

Then in December 2014, Byers saw a Koori Mail advertisement from the Indigenous Marathon Project (IMP), which every year selects a group of young Indigenous men and women to complete the New York City Marathon with just six months of training.

It uses the marathon as a vehicle to promote healthy lifestyles to Aboriginal and Torres Strait Islander people and says it “uses running to change lives”.

It sounded just right to Byers. “I really needed something to get me going, I needed something to get all the stress out of my life,” she told the conference. “I needed to set myself a goal.”

There was just one problem.

“The only running I’d ever done was on a netball court and running after my kids.”

Still, she applied and headed for an IMP trial day at Coffs Harbour. She finished the three-kilometre course, but mostly walking. She could only run in spurts between pain and cramps, and didn’t think there was a chance she could qualify.

But, as she said in the blog post, she also had a one-on-one interview with coach Mick Rees.

“He wanted to know why I wanted to be part of the IMP team. I told him everything … the drinking, the smoking, the unemployment, the teenage mum, being unfit, overweight, my learning problems … and being over it all, over my life and wanting a change.

He then asked me what being in the IMP would do for my life. I told him I wanted the opportunity to train as a fitness coach and that it would challenge me out of my very unhealthy, comfort zone – physically and psychologically.
Then the crunch question, he asked “what would I do for my community?” I said “I want to be a role model in my community, for anyone who wants or needs it, and because of my experience as a teenage mum, I also want to help young mums to live a happier, healthier lifestyle.”

Rees told Croakey that he had deliberately set the trial on a waterlogged oval across the road from the athletics track, to see how the candidates responded to tough conditions. He said he gave Byers every opportunity to quit. “I was saying ‘you can pull out if you want’,” he remembered. “She just wouldn't stop.”

Showcasing resilience

He said: “After seeing what she did and hearing her speak in the interview, I saw an unbelievably tough and resilient woman who had just never been given an opportunity. All she needed was an opportunity to showcase her resilience.”

A month later, she got a phone call to say she was one of 12 from across Australia who had been selected for the 2015 team.

“Then the hard work began,” she told delegates.

The photos below from her slideshow show both the pain and the joy that led her through training (8 hill sprints, three 5 kilometre runs, two 10-20 kilometre runs every week) and via a half marathon in Canberra (“I came last but I was so proud I finished”), the Sydney City to Surf, and a 30 kilometre bush run outside Alice Springs.

And then New York, the world’s most popular marathon, where she broke down in tears as she finished.

“The tears were joy. Joy and (being) proud of myself for finishing….not just for myself but for my kids and family and everyone who supported me, especially my partner,” she told Croakey.

What kept her going when she began to struggle in New York was a sign that said: “When your legs are tired, you’re running with your heart.”

And she has plenty of it. Her eyes light up as she talks about breaking through the pain barrier as she runs. “I love the pain, I just love it. It hurts, but with the pain I know that I’ve done something.”

The journey isn't over

As part of the IMP, she completed her Certificate 3 in Fitness, and Level 1 Athletics Coaching Certificate, as well as Senior First Aid and CPR. Participants aren’t allowed to compete in New York unless they’ve done these.

Rees also worked with her to stage a Fun Run in Casino, that attracted 120 participants, including her sister “who got out of her hospital bed to walk it in her pyjamas,” he said.

Rees said the program is not just about taking young Indigenous people on a fantastic trip to New York, but about empowering them personally and then to go back into their communities to help increase levels of physical activity, not just for the impact on obesity and fitness rates but for the impact exercise can have on mental health issues that have led to high Indigenous suicide rates.

“When she crossed the line in New York, she crossed it as a different person,” Rees said. “She’s starting now to understand how much of a community asset she is.”
This year Byers completed her Certificates in Primary Health Care (levels 2 and 3) and has now taken the big step to move way from family to take up the job at Walgett.

“It took me a really long time to work out that (working in Aboriginal health) was what I wanted to do in my life,” she told Croakey, but acknowledges the move away has been difficult and she’s struggled in recent months to keep up her training regime, nervous of new surrounds.

**Success in quitting**

Many of the issues she has had to dealt with in her own life and which will now come up in her work were under discussion at the conference, with its theme of Caring for Community and focus on **Tackling Tobacco and Chronic Conditions**.

She was particularly struck by the presentations highlighting ways to reduce smoking and talked to the conference herself about the the large role that smoking continues to play in the social and family life of many Aboriginal and Torres Strait Islander people.

Byers said she had to distance herself a little from family while she got through the hard days of quitting. She would still visit, but not stay as long.

“I had to quit smoking, I knew I had to do it, not only for myself but for my family as well, my kids,” she said. “But it’s really hard when your whole family smokes.”

But she made it. “I can be around them today and not even care (about smoking),” she said. “I can’t even stand the smell of smokes anymore.”

And Byers is now inspiring her siblings to make changes too.

“My sister wants to start running as well, my brother,” she says. “I think a lot of my family has been wanting to change. They’re always going to have that negative thought telling them they’re not good enough to change, but if you believe you can change, you can.”

Below are some photos and tweets from her presentation, and watch her interview at the bottom of the post.

**Running at Alice Springs**

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

Running with heart and health: Eileen's story of a life-changing marathon

At Coffs Harbour

EILEEN BLYERS
TO BE FIT AND HEALTHY

COFFS HARBOUR TRIAL 2015
In New York City

Running with heart and health: Eileen’s story of a life-changing marathon

#AHMRC16
You can track Croakey's coverage of the conference here.

Running with heart and health: Eileen’s story of a life-changing marathon

#AHMRC16
You can track Croakey's coverage of the conference here.

#AHMRC16 tweets

Rachael Havlant @RachaelHavlant • 26s
Eileen Beyers thanks for sharing your amazing journey on the IndigenousMarathonProject. What an inspiration to your community

#AHMRC16

Marie McInerney @mariemcinerney • 4m
Tears welling in room with the inspiring story of Aboriginal health worker and marathon runner Eileen Byers #AHMRC16

Aboriginal health worker and marathon runner Eileen Byers on
Using stories to tackle tobacco and related diseases: Hearing from the AHMRC conference

Marie McInerney writes:

Stories from Aboriginal people who have had cancer are at the heart of two programs being rolled out across Australia to help combat high cancer mortality rates among Aboriginal and Torres Strait Islander people.

The Our Lungs Our Mob and Women’s Business programs are being delivered nationally by the Aboriginal Health Council of South Australia Inc (AHCSA) for Cancer Australia.

They were showcased recently at the Aboriginal Health and Medical Research Council of NSW conference in Sydney, Tackling Tobacco and Chronic Conditions.

AHCSA Maternal Health Tackling Smoking Project Officer Mary-Anne Williams said the programs feature everyday stories and resources about cancer, and resonate strongly for staff at the organisation after AHCSA lost its widely respected, long-standing CEO Mary Buckskin to cancer last year, aged just 57.
“She touched many peoples’ hearts”

Mary Buckskin was one of the first Aboriginal health professionals employed in South Australia, firstly as a nurse, then as Aboriginal hospital liaison officer, clinical educator and policy adviser.

She was hailed in this obituary for helping to establish critical partnerships, projects and initiatives at the Council of Australian Government’s National Reforms in Aboriginal Health and being instrumental in South Australia’s bipartisan signing of the Oxfam Closing the Gap Statement of Intent to address Aboriginal health inequities.

“She was very dear to us all, she touched many peoples’ hearts and we really miss her,” Williams told Croakey at the conference.

“When she was diagnosed, she sent out an email urging everyone to get their health checks, so we’re really engaged personally and professionally on these programs. It’s a part of the healing, to get the information out as far and wide as we can.”

Our Lungs Our Mob and Women’s Business workshops are being offered to Indigenous health workers and Aboriginal community controlled health organisations so they can in turn offer them to their own local communities, whether as formal presentations or informal yarning sessions.

Coming with step-by-step instructions (see the Our Lungs Our Mob resource), they aim to provide culturally relevant and appropriate tools and resources to combat lower screening and later diagnosis rates among Aboriginal and Torres Strait Islander people that have been limiting their options for treatment and contributing to higher mortality rates.

The need is high: between 1998 and 2012, the cancer mortality rate for non-Indigenous Australians fell by 10 per cent, but rose for Indigenous Australians by 16 per cent. Recent research found that cervical cancer screening rates for Aboriginal and Torres Strait Islander women had not improved at all through the 25 years of the National Screening program.

Archie’s story

In this video (below) made for the Our Lungs Our Mob program, Archie Roach talks in detail about how he initially wanted to ignore the symptoms of lung cancer that he was experiencing – “sometimes gasping for breath”.

He also describes how he felt when the diagnosis was delivered. “To be honest, I was pretty scared,” he said.

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You can track Croakey’s coverage of the conference [here](#).

Using stories to tackle tobacco and related diseases: Hearing from the AHMRC conference

#AHMRC16

Croakey

“Conference News Service”
Archie then describes the surgery, which was much less invasive than he had feared but nonetheless knocked him around for some time.

He says his message is: If you’re starting to show symptoms, you need to go and see a doctor, have a thorough medical examination, because “if you leave it too long, it could kill you.”

(See also this previous Croakey story featuring Archie and his physician, that discussed the impact of trauma and racism on health, and the experience of Indigenous peoples in unequal access to and treatment in the health system.)

**Bobby’s story**

In another video, a young man called Bobby describes his experience, of how scared he was that he had cancer when he began to cough up blood. In fact, it turned out to just be a chest infection, and a very valuable prompt to give up smoking.

The videos are used to spread key messages and prompt discussions in workshops, suggesting possible take home messages about Bobby’s experience:

- coughing up blood, chest pain and ongoing cough are lung cancer symptoms
- Bobby initially delayed seeing a health professional
- Bobby was given a chest X-ray to investigate his symptoms
- experiencing these symptoms may not mean you have lung cancer
- smoking is a risk factor for lung cancer
- quitting smoking is important.
Hearing from Merle and her family

In this video, Merle and her daughter Valda talk about the impact on their family of Merle’s cancer diagnosis and treatment and what the recovery process involves.

Suggested take home messages include:

• ongoing cough and shortness of breath are lung cancer symptoms
• importance of family support during diagnosis and treatment.

The aims are to increase community awareness of the symptoms of lung cancer, so participants:

• understand some of the myths about cancer (such as that cancer is contagious, or can be caused by broken bones or bruises, or is a result of payback)
• understand the risk factors for lung cancer
• name lung cancer symptoms
• identify who they can talk to if they have symptoms that may be lung cancer
• understand the benefits of diagnosing lung cancer at an early stage.

Williams says:

“It's not rocket science. I always say I'm not a cancer specialist but I'm here to deliver this education around awareness about cancer.

Now is the time to start talking about cancer as we know how hard this is and it isn’t discussed often enough within our families. AHCSA plays a role in generating these sensitive discussions within the communities.

It's about trying to engage with local people, having local ambassadors, trying to find the right local person to engage with.

With a lot of the Aunties or Elders that I work with in the Women's Business program, when I ask at the end what they're going to do differently, they all say: 'I'm going to tell my grannies, tell my nieces, going to talk to my family about the importance of having checks.'
Many of our services are overstretched and under-resourced so it’s finding the right person and using those ambassadors to drive the messages.”

The programs come under the newly launched National Aboriginal and Torres Strait Islander Cancer Framework. See its priorities:

1. Improve knowledge, attitudes and understanding of cancer by individuals, families, carers and community members (across the continuum)
2. Focus prevention activities to address specific barriers and enablers to minimise cancer risk for Aboriginal and Torres Strait Islander peoples
3. Increase access to and participation in cancer screening and immunisation for the prevention and early detection of cancers
4. Ensure early diagnosis of symptomatic cancers
5. Ensure Aboriginal and Torres Strait Islander people affected by cancer receive optimal and culturally appropriate treatment, services, and supportive and palliative care
6. Ensure families and carers of Aboriginal and Torres Strait Islander people with cancer are involved, informed, supported and enabled throughout the cancer experience
7. Strengthen the capacity of cancer related services and systems to deliver good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander people.

Evaluation matters

Williams said evaluation is a very important part of the Our Lungs Our Mob program. Evaluation forms are handed out at the end of each workshop and followed up after two weeks and again after three months.

She said: “We’re asking: ‘were there more people coming in for health checks, do they see people coming in asking for more information about cancer, do they see an increase in people talking about cancer?’” Cancer Australia will then do a national evaluation.

“ACHSA is very proud to be delivering this,” she said. “Cancer is very common in all Aboriginal communities and it particularly affected us last year with Mary passing away from cancer. So we’re really proud that we’re able to take this on, because cancer doesn’t discriminate, it affects everyone and we’ve not been untouched by it.”

The AH&MRC has also produced an 18 page booklet, “Culture, Cancer, Caring – Inspiring Stories for our Mob” that highlights the work being done across New South Wales by Aboriginal health workers and community controlled health services to reduce the burden of cancer.
Addressing smoking in the Illawarra

The conference also heard about moves to create a more smoke-free environment at the Illawarra Koori Men's Support Group, where Elders recognised smoking was causing both economic and health harms, but no-one wanted to discourage smokers from being involved in the group.

“We weren’t doing this to punish men who smoke,” said Stuart Porter from New South Wales who led the project.

“They’re all welcome but we’re trying to protect the health of young people, people who don’t smoke and those who are trying to quit. We’re serious about not smoking but not that serious that we don’t make smokers welcome.”

The initiative began with moving anti-smoking information outside to where the smokers were, acknowledging also that many were not seeing social media messages or watching TV campaigns.

With the help of high school students, the group did an “environmental scan”, taking photos of where butts were being left and stopped smoking near doorways or food, even outside.

The group also talked about how much support was being offered to its members who might want to quit, and how much it could shift expectations.

It’s an issue being increasingly discussed between health and social services, to challenge what VicHealth has described “the cultural acceptance of high smoking rates within marginalised communities”.

The group introduced a question on the form for new members asking ‘do you smoke?’. If the answer was yes, they were asked ‘would you like help to give up?’.

“Some were drinking 14 cups a day of coffee, dealing with custody issues, and were stressed to the eyeballs,” Porter said. “I try to get them to cut down caffeine, (and say): ‘You told me you got off the ice, you got off the alcohol: if you can do that, you can get off smoking’.”

Porter presented some of the lessons of the project, including the need to bust myths (such as that ‘rolling your own’ is safer for health) and the value of hearing Elders’ stories about the introduction of tobacco in their lives, such as one who talked about cigarette machines being introduced on the mission he grew up in.
Dead or Deadly?

The Waminda South Coast Women’s Health and Welfare Aboriginal Corporation also talked about its **Dead, or Deadly program**, an ongoing 10-week intervention for Aboriginal women, which covers health, happiness, a fitness program, diet, self-esteem and goal setting.

One of its most effective messages to women who were worried that they would put on weight if they gave up smoking was to **cite evidence** that they would have to gain over 40 kilograms above their recommended weight to equal the risk of heart disease posed by smoking.

Watch this fabulous video:

And **watch another video** about the Solid Mob’s Amazing Race to Happy, using game-based interactive learning to engage young people in health promotion, run by the Bullinah Aboriginal Health Service.
You can track Croakey's coverage of the conference here.

From the Twittersphere

Rachael Havriant @RachaelHavriant  ·  May 3
Amazing Race to Happy for school kids by Bullinah AMS. Fun way to learn health promotion messages #AHMRC16

Marie McInerney @marlemcinerney  ·  May 3
"Dead or deadly" - Aboriginal health workers fro Warninda South Coast talk about how they’ve quit smoking #AHMRC16

A-TRAC team @ATRAC_team  ·  May 3
Aboriginal Community Controlled Health Services leading the way in culturally appropriate health care #AHMRC16
You can track Croakey's coverage of the conference here.

Aboriginal people = 24% NSW prisoners: were big focus of cultural support in move to smoke free prisons #AHMRC16

Some promo/health merch at #AMHR16, including pack of cards for smoke-free Indigenous prisoners made in Long Bay

Class of #AHMRC16
Conference participants had mixed views about the Federal Budget’s tobacco tax increase.

Marie McInerney @mariemcinerney · May 3
'Good & bad in tobacco tax hike: we’re going to have to work extra extra hard to help our mob to quit'. #AHMRC16 on #healthbudget16

Marie McInerney @mariemcinerney · May 3
Mixed views at #AHMRC16 on the tobacco tax hike in #healthbudget16 - 'discourages smoking' but 'takes food from kids' mouths'

Jon Wardle @wardlejon
@mariemcinerney all for raising excise, but health funding cuts make it harder to get help to quit than ever. Without support it can exploit
Conference puts spotlight on improving care for Aboriginal people with chronic pain – and for children with autism

Image from a short film, Understanding Autism

In this report from the recent Aboriginal Health and Medical Research Council of NSW conference in Sydney, journalist Marie McInerney details efforts to improve the care of Aboriginal people with chronic pain and children with autism.

Better pain management

Many Aboriginal people with chronic pain do not receive effective care; however, efforts are underway in NSW to improve access to effective, culturally appropriate help.

The focus is also on reducing the need for people to travel long distances to metropolitan centres.

As the conference heard, developing more accessible, appropriate services requires an understanding of the current barriers to care.

Some of these are detailed in the following slide, presented at the conference by Aboriginal Health Education Officer Ellis Bradshaw, from the Lismore Base Hospital in northern NSW.
Bradshaw told a conference session on chronic pain: “We knew if we were going to run a program for the community, we were going to have to take it to them.”

He described workshops being run by Lismore Aboriginal Health – Gurgun Bulahnggelah – as part of a growing effort in the state to address high levels of often un-managed chronic pain in Aboriginal communities.

The session was run by New South Wales Health’s Pain Management Network, which is looking to partner with Aboriginal health organisations and programs, like that run by Bradshaw in Lismore, by providing training and resources that Aboriginal health workers can take away and tailor in language, style and content for their communities.

It’s hoping also to develop culturally appropriate and relevant resources like the video below on managing back pain. It was produced by the Western Australian Centre for Rural Health, in association with Curtin University and the Geraldton Regional Aboriginal Medical Service.
Overuse of opioids

An estimated one in five Australians lives with chronic pain, according to Professor Michael Nicholas, Director of Pain Education and Pain Management Programs at the Pain Management Research Institute at the Sydney Medical School and co-chair of the Pain Management Network.

This figure rises to one in three people for Aboriginal and Torres Strait Islander people – the same rate experienced by non-Indigenous Australians aged over age 65 years.

There is also over-representation of Aboriginal and Torres Strait Islander people in use of opioids for pain management, Nicholas said – making up one in ten of those on opioid programs.

The Network believes that this over-representation is for similar reasons that opioid use is so high generally in rural and regional areas (up to ten times the level of prescribing compared to metropolitan areas).

“A lack of alternative options is the main reason,” Nicholas told Croakey after the conference. “That’s why we’re trying to push access to broader pain services in more remote areas.”

When the Pain Management Network was set up in 2012, NSW had 11 pain clinics, all along the east coast, and only three in rural or regional areas.

There are now 19, with more on the way, and with tele-services extending the reach into regional areas.

The Network is now seeking to partner with more Aboriginal health services and communities, and has worked to date with organisations on the north coast, Redfern, Moree, Broken Hill and the south coast.

Holistic approaches

Pain is not a separate health entity for many Aboriginal people, according to Pain Management Network Manager Jenni Johnson.

“It’s part of a broader social, emotional and historical context and interwoven with Country and way of life,” she says.

Grief and loss are linked heavily with pain, including loss of culture, language, land and identity. Pain can result in shame and isolation.

There’s also, as Bradshaw’s slide noted, mistrust of the health system when seeking help for pain, and mistrust or misunderstanding about the role of medications.

“Key messages about pain need to be simple – they need to be delivered in the context of story telling and shared experience to have meaning,” she said.

In the main, she said, the program has learnt that clinic environments are not suitable. Nor is a “fly in and fly out” approach from specialists.

Communities need a long-term commitment, and learn better from community leaders, with the support of an expert pain clinic.
Nicholas said the reason pain clinics were so centred on metropolitan regions is that they require a multidisciplinary team.

“In country towns, you might have a GP and a nurse, but not a physio or psychologist. You can find ways to fill those roles as much as possible from the people who are available, but they need training.”

Thus the Network is seeking to develop, in collaboration with the AH&MRC and through Aboriginal community controlled health organisations, ways of running pain programs in communities, “so they don’t have to face coming down to Sydney or going to one of the big centres where experience has been that they don’t want to do that,” he said.

Under the proposed program, Aboriginal health workers would be trained in pain management skills and approaches, which they can then translate as they see best for their communities.

“At the moment, Aboriginal people are not accessing available services as much as their numbers suggest they should, in which case we’ve got a delivery problem,” he said.

The objective is to have pain services “that are accessible to people across the state at a reasonably consistent level so it shouldn’t matter where you live or what you earn as to what services you get, it will depend more on your need,” he said.

“We obviously can’t have a big pain clinic in every town, but there’s no need: we can project tele-services and engage local services.

“They don’t have to be hospital-based, we’re actually trying to demedicalise (pain management), to show there are non-drug alternatives.”
Key messages

- “Tell them they have to move more”
- “Got to try to reduce my drugs”
- “Gotta talk to someone”
- “Look after your mind, then pain will be better”

Bring everyone onto the same page

Focus on autism

Yvonne O’Neill has played rugby league on the international stage for Australia and has artwork on display in the Vatican.

But her passion now is to spread the word in Indigenous health services and communities about the need for early diagnosis and management of autism spectrum disorder (ASD) so the next generation of Aboriginal and Torres Strait Islander children can achieve their ambitions.

“I’ve been very fortunate,” she says, “but I want them to do better.”

For that to happen, she says mainstream health services will have to start looking at children with ASD with fresh eyes, to avoid stereotypes and to allay family fears that they are ‘naughty kids’ who may be taken away by authorities if behaviour issues are reported.

O’Neill is an Aboriginal woman from Goodooga in NSW. Her mum is an Yuwaalaraay/Kamilaroi woman and her dad, well-known Indigenous artist Tex Skuthorpe, is a Noonghaburra man.

In 1995, she became the first ever Indigenous woman selected for the Australian Women’s Rugby League team. She continued to play at the international level for ten years, and helped found the Indigenous All Stars women’s rugby league side.

It was while working as head of Indigenous education at St Joseph’s Nudgee College, a Catholic boarding school for boys in Brisbane, that she finally followed her father’s calling and picked up a paintbrush.

In 2010, she was commissioned to paint a 2.1 metre wooden cross for the thanksgiving ceremony in Rome that marked the sainthood of Australian nun Mary McKillop. Another commission for the Vatican followed, and her canvas painting depicting a dreamtime story now hangs in the Vatican Museum.
Now she is one of three Early Intervention Indigenous Liaison Officers based at Autism Queensland, and is charged with raising awareness nationally about the prevalence of autism in Aboriginal and Torres Strait Islander communities and the benefits of early intervention for children aged 0-7.

O’Neill and her colleagues were recently also given responsibility for promoting awareness around a range of other disabilities, including Down syndrome and cerebral palsy, in the lead up to the roll-out of the National Disability Insurance Scheme (NDIS).

In many communities, she said, there’s a tendency, particularly among non-Indigenous services, to assume that a child presenting with developmental issues has whatever is prevalent in the community, whether it’s foetal alcohol spectrum disorder (FASD) or attention deficit disorder.

“People need to start looking at Aboriginal and Torres Strait Islander kids with fresh eyes, when they walk into a surgery or health service, so they’re getting a fresh evaluation every time they go there, rather than being stereotyped,” she said.

While Indigenous patients generally are at risk of being stereotyped by health services, she says the stakes are higher when it comes to children, given the benefits that can flow from early intervention for a range of illnesses and disabilities, including autism.

To foster awareness, the team has created the film below, Understanding Autism. It follows the journey of an Indigenous boy called Ned through the process of diagnosis.

Other resources, including picture books, about autism for Aboriginal and Torres Strait Islander children and families can be found here.

When it comes to ASD, O’Neill says the key is to give families and service providers in Aboriginal communities the right tools, language and information to be able to go to their GP or paediatrician to “get the right diagnosis and not be scared of the process”.

“If all anyone in the community tells you is that your child is naughty, always mucking up, and no-one has any alternative diagnosis because ASD is not even on the radar, the kid gets labelled,” she said.

“The more we can reach into communities, building awareness and capacity, the more that service providers who are there on the ground can help families to navigate that system in a safe and culturally appropriate way.

“If they have the diagnosis, then they can have the proper care plan, so they can be set up on a successful pathway, not be disadvantaged from the get go. Otherwise we are setting them up to fail.”
Twitter Analytics
Below are the Twitter analytics from #AHMRC16, and you can also read the Twitter transcript. Thanks to all tweeters!

The #AHMRC16 Influencers

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<th>Top 10 by Mentions</th>
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The Numbers

1,397,515 Impressions
316 Tweets
113 Participants
1 Avg Tweets/Hour
3 Avg Tweets/Participant

#AHMRC16 Participants

Croakey Conference News Service

- Reporting by Marie McInerney
- Editing by Melissa Sweet
- Layout and design by Mitchell Ward