Sharing stories of success, strengths and need

NSW Aboriginal State-wide Cancer Forum

May 2018

On the country of the Gadigal people of the Eora Nation, in Sydney.
The Aboriginal Health and Medical Research Council of NSW convened the forum:

1. To hear from participants about what works in providing locally led support programs for people with cancer and their families.

2. To learn what resources, training and support are needed to support Aboriginal people living with cancer and to strengthen locally led cancer support networks in NSW.

3. To develop a communications platform moving forward.

4. To facilitate networks and linkages.

Welcome to Country and Introductions
Uncle Ray Davison provided a warm Welcome to Country, and delegates were also appreciative of the Koomurri Aboriginal Incursions dancers.

“We are listening to what you say,” the AH&MRC’s Dr Kate Armstrong told participants. “We’re passionate about getting your voices out.”
Sharing personal stories

Dhinawan Baker

As MC over the two days, Dhinawan Baker, a descendant of the Gamillaroi Bigambul tribe, shared personal stories and cultural knowledge. He spoke of the impact of cancer upon his family, and the importance of managing family relationships through stressful times.

He has learnt the importance of “surrounding yourself with positive people, putting yourself in a positive environment and setting yourself goals”.

Dhinawan also talked about the importance of cultural connections and travelling around the world as part of his family’s collective healing.
**Sharing personal stories**

**Desmond McGrady**

Desmond McGrady, a Kamilaroi man from Queensland, generously shared his experiences since being diagnosed with a rare and aggressive form of head and neck cancer.

After he began feeling unwell with persistent headaches and sinus and breathing problems, it took some time and effort before a proper diagnosis was made.

Desmond described the importance of supportive networks during intensive radiotherapy and chemotherapy that lasted several weeks. He acknowledged a friend who joined him on regular walks and through his treatment journey.

“It’s always good to have someone beside you through this process, instead of being alone in a room ... having someone who is willing to sit with you and not look at the time and hear your concerns...really helps with the process.”

**Desmond McGrady**

Desmond stressed the importance of traditional healing practices, including massage, in helping him to regain strength and weight. Desmond also found it important to set positive goals.

“I kept telling myself, by 2016, I want to be on a riverbank, fishing and camping and laughing with my family. And by Christmas, I was sitting on a riverbank, and I was fishing and I was camping with my family... I have good days and I have some bad days and I struggle with emotions... but other days are filled with happiness and laughter. I have discovered just how strong I am and how much determination I have. Each day is a gift that I am truly grateful for.”

**Desmond McGrady**
Desmond explained how it has been important to him to share what he has learnt and to contribute, whether by participating in research or through participation in support groups.

He stressed the importance of Indigenous cancer support groups “where we can have a yarn”, and also the value of inviting professionals to speak to such groups, for both patients and carers.

Watch the interview below with Desmond.

https://www.youtube.com/watch?v=y1PcLmSBvEI
Ngununggulla – working and walking together

The cancer care team at the Illawarra Aboriginal Medical Service, Wollongong

Aunty Trish Levett and Kyla Wallace gave a powerful and inspiring presentation about the wide-ranging scope of their work in the Illawarra region.

Their positions with the IAMS cancer care team are part-time and funded as a pilot project by the Rural Doctors Network of NSW. They hope to develop secure, sustainable funding for full-time positions.

Their passion and commitment to their work and community shone through – as did their vision for sharing their work widely, across NSW and nationally.

“We have the best job in Australia... we are so proud of what we do and we would love for everybody else to be able to do what we do…”

Kyla Wallace

They began their presentation by explaining the meaning of Aunty Trish’s artwork, Ngununggulla – working and walking together. The two women are represented by the figures in the middle of the painting, which acknowledges the ocean of the Illawarra, men and women with cancer, and the chemotherapy unit at Wollongong hospital. Hands in the painting represent “the support within our community”.

The cancer care team was established after one of their colleagues was diagnosed with cancer and realised how little support there was for Aboriginal people with cancer in the Illawarra.

Aunty Trish and Kyla provide a range of health promotion, prevention and early intervention and support services to patients and their families and carers.

They also are advocates for patients and their families, engaging with services and other organisations.
“We liaise with whatever service is running out there and work with them.”

Kyla Wallace

Their work includes:

- Holding a monthly yarning circle for mob with cancer, so they can have a yarn, do cultural activities, and have some respite.

- Connecting people with country and culture, for example, with visits to healing and sacred sites on Gundungurra country, and with healing ceremonies and bush medicine.

- Mammogram days are held twice a year at Breast Screen NSW, with arts, crafts and food to provide a safe and welcoming environment.

- Bling a Bra is another health promotion activity promoting breast cancer awareness and screening through community displays of painted, decorated bras.

- Working with the Koori men’s group in the Illawarra; for example, holding a men’s health day with a focus on bowel cancer screening.

- Participating in a local Melanoma March.

- Providing support to patients, their families and carers throughout the cancer journey, attending medical appointments with patients, and referring them to other services where necessary.
Advocating on behalf of patients and their families; for example, ensuring hospital staff understand their cultural needs, and arranging for pro bono services where necessary (such as will preparation).

Producing and distributing accessible, culturally appropriate resources.

Funeral planning and grief counselling – which is not time limited, but is provided until the families are ready for this to stop. Individual and group counselling sessions are provided, mostly not in the office but by the river or at the beach.

The pair described how they do all this on limited funds – through visiting op shops, finding resources in Mother Nature, and approaching local businesses for funding.

“I want the message to get out all over the place and I want to be able to share the resources and what we do to help support anyone else who wants to start to run a few programs like we do.”

Kyla Wallace

“We want our service in every AMS in NSW and then we will take it to every single state throughout Australia.”

Aunty Trish Levett
Watch the interviews below, where they also talk about the importance of their strong relationship for their work.

https://www.youtube.com/watch?v=9NK0g05l4Vo

https://www.youtube.com/watch?v=t4tBpFitEN0

Commenting on their presentation, researcher Kalinda Griffiths said it showed the importance of documenting the full scope of their work, including the connections and relationships processes.

Yarning about cancer: setting up support groups in Aboriginal and Torres Strait Islander communities

Kim Pearce, Cancer Council NSW

In 2017, Aboriginal women from across NSW participated in a two-day yarning circle in Sydney, with the aim of supporting them to then set up yarning circles in their own communities.

The yarning circle workshop was organised by Cancer Council NSW, with a Ralph Lauren Pink Pony grant from Cancer Australia. It included art and cultural activities, and presentations by health professionals and woman.

Since then, two workshop participants had worked to establish a yarning circle for women affected by breast cancer in the Galambila and Biripi communities, Kim Pearce, one of the workshop facilitators, told the Forum.
The women worked closely with their local AMS and the regional office of the NSW Cancer Council in setting up the yarning circle.

Kim said the evidence showed that peer support was beneficial for people with cancer, in allowing them to share their experience and learn from one another.

She said that it is healing to provide a safe space for people to share their cancer journeys.

An evaluation found the workshop increased participants’ knowledge about the Cancer Council of NSW’s role in supporting Aboriginal people, their skills in setting up a group agreement, and their confidence in starting a yarning circle.

Kim presented some of the art work from the yarning circle and Wendy Brown’s message.

Another story from the yarning circle.
As part of preparation for the workshop, Kim said she and her co-facilitator from the Cancer Council did cultural awareness training, which is now part of in-service training for all their staff.

Kim said the NSW Cancer Council is striving to do more work on the ground with Aboriginal Medical Services.

Kim said a presentation to the workshop by Aunty Trish Levett and Kyla Wallace was “a gift” that had helped others to see the value of having a dedicated cancer care centre operating out of an AMS.

Watch this interview with Kim

https://www.youtube.com/watch?v=R1XGT-rQ6R8
Hearing from participants

Workshop participants talked about the services that are available in their areas, as well as those that are lacking. Discussions revealed inequities between communities in their access to health and other services, including transport services for patients. Some discussed the stresses for patients of having to travel long distances from home for treatment, sometimes leaving their communities for the first time.

Some participants stressed the importance of working with young people, in preventing the uptake of smoking. Many wished to start yarning circles and other cultural activities in their areas, including for the children and families of those affected by cancer. Some communities already had yarning circles in operation. Some participants said they used a range of social media platforms as part of their work, and others did not. Participants’ commitment to caring for their communities, despite often having limited resources, shone through.

“I’m really happy to be here because already, I’m seeing there is so much that can be done. People are so friendly and helpful in offering their experiences and giving us contact details so I really appreciate all that. It’d be really good if we can support each other as a network in the future with this.”

Jill from the Walgett AMS

“There’s some really great ideas I can take back home and do with no money - its just about being creative and thinking outside the square a little bit, so thank you.”

Courtney from Forbes said she appreciated getting ideas for what could be done, using limited resources and creativity.
Kyla Wallace stressed the importance of making connections and sharing experiences and resources.

“This is not just a talk fest, this is really where you get some stuff done.”

Kyla Wallace

Professor Gail Garvey said her research team at the Menzies School of Health Research wanted to support services, and described the development of an alternative pathway to bowel cancer screening. Researchers hope to recruit 50 primary health care services with a big Aboriginal population to deliver the Indigenous bowel cancer screening kit. See: https://www.indigenousbowelscreen.com.au/community/

“We’re interested in connecting and supporting services because we’re not just doing research for research’s sake; we’re doing it to make a difference for our mob. Cancer has affected my family, as I’m sure it has everyone else in this room and we have to actively do something about it. We have a National Indigenous Cancer Network, an online resource that we constantly update and we’re extending that to an International Indigenous Cancer Network.”

Professor Gail Garvey
Evidence-based approaches

Dr Kalinda Griffiths and Professor Gail Garvey from the Menzies School of Health Research, Dr Rowena Ivers from the IAMS, and Warren Frost from the AH&MRC presented on different aspects of data.

Professor Gail Garvey said a tool is being developed to identify the needs of the families and carers of Aboriginal and Torres Strait Islander people with cancer. She invited services interested in this work to contact her.

“What we want to do is gather the stories of the caregivers of Indigenous cancer survivors and find out what their needs are, how would they like to be supported, what information do they need to help them walk the road and the pathway with the cancer survivor.”

Professor Gail Garvey

She stressed the importance of those affected by cancer being integrated into the work of researchers, and invited anyone interested in being an Indigenous Cancer Ambassador to make contact.
“To get a better outcome for our mob, we have to deal with lots of different things, it’s multi-faceted, it’s multi-level; so we have to deal with the political environment, we have to deal with the healthcare system; we have to deal with the social cultural sort of issues; we have to deal with communication and the individual’s experience; we have to deal with a whole range of factors.”

Professor Gail Garvey
Dr Rowena Ivers, a GP at the IAMS, presented on the importance of local data.

She said the team used qualitative methods, such as listening to story telling and yarning circles, to inform their evaluation and work.

Local data is important for helping to monitor and evaluate programs, to give feedback to community, and to monitor the follow up and care of patients.

“Why do we collect information about our services? When you are setting up new programs, it’s really good to work out where you are at, to collect some data, to work out the level of need in your community, and it helps you plan programs. Funding agencies want data.”

Dr Rowena Ivers

Establishing a cancer group on the IT system enabled them to invite members to functions and events, and helped to create a peer community of people with cancer, which some people found very useful.

The IAMS had also made a clinical item for any cancer care consult, so every such interaction could be logged and documented to funding bodies.

Dr Ivers also discussed the use of incentives, such as gifts and pamper days, to encourage community engagement with screening and services.

Dr Rowena Ivers (L) with Kyla Wallace and Aunty Trish Levett
Warren Frost, ICT/IM manager at the AH&MRC presented on data collection and systems.

Warren discussed the role of data in cancer prevention, screening, treatment and support, and recommended the RACGP National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people, available here:


“We need to be able to record this sort of information so that we get a story, we get a picture of how many people have been tested, what sort of treatment processes have been applied, what sort of surgeries have they had, were they successful? Was treatment successful? Was vaccination successful in preventing the onset of particular cancers? That’s the data that I’m excited about.”

Warren Frost

Warren also described the need for better data on families and carers, also highlighted gaps in the provision of transport services.

“She need to be able to record this sort of information so that we get a story, we get a picture of how many people have been tested, what sort of treatment processes have been applied, what sort of surgeries have they had, were they successful? Was treatment successful? Was vaccination successful in preventing the onset of particular cancers? That’s the data that I’m excited about.”

Warren Frost

“Transportation can be hit and miss. Some of our services have transportation but quite a few don’t, and that becomes a real problem, particularly where you have got to transport a person from a home or AMS to a hospital hundreds of kilometres away. That becomes really problematic.”

Warren Frost
Warren spoke from his personal experience about the importance of developing a better understanding of grief as part of the story of cancer patients.

Commenting on his presentation, Kyla Wallace said: “When you are talking about grief, we need to be mindful that grief isn’t something that you suffer only when people die. Grief happens in any relationship breakdown. We need to keep a broad focus on grief and not only tie it into dying.”

A supportive care needs assessment tool

Dr Suzanne Moore and Professor Gail Garvey from the Menzies School of Health Research.

Services have been invited to test the use of a new tool for assessing the supportive care needs of Indigenous patients.

Researchers from the Menzies School of Health Research are developing the tool.

Dr Suzanne Moore told the Forum that routine screening for psychosocial problems may lead to better patient outcomes, improve quality of service delivery, and decrease health care costs.

Screening is best practice recommended by Cancer Australia and other groups, she said.

Research had shown high levels of unmet needs among Indigenous cancer patients, including physical, psychological and cultural needs, as well as other issues such as money worries.
A Cancer Australia grant was funding a national implementation study of the new tool, SCNAT-IP.

It includes 27 questions in four domains – physical, psychological, hospital, and information – and is to be administered verbally.

Dr Moore said the tool could be used in other areas; for example it could be modified to suit people with other conditions, such as chronic diseases.

Discussions highlighted the importance of demonstrating to patients and staff that the tool aimed to improve services and was not just another data collection task put on busy staff.

“The tool has been developed; now we are training people and saying if you would like to implement this in your service, we will support you in whatever way that we can... by providing you with the tool and providing you with some additional resources about how it might be used... What this tool does is try and identify from the patients’ perspective what support they would like.”

Professor Gail Garvey

“We’re looking forward to using this to guide us.”

Kyla Wallace commented that the tool would be useful.
Strengths cards exercise

With Kyla Wallace and Aunty Trish Levett

Workshop participants were asked to select cards beautifully inscribed with words such as “acceptance”, “self care”, “respect” and “kindness”, and to talk about whatever came up for them.

“There is no right or wrong answer with these cards,” Kyla Wallace told participants. “When you get a card it’s just about reflecting back.”

Narelle Hall from Murrin Bridge talked about “strength”, and how the small AMS where she works strengthened community by providing many services and outreach programs, despite having a doctor visiting only one day a week.

“Our strength is built daily, weekly because of the need for our mob to be better, to be healthier. That to me shows great strength because we do more beyond our scope, really.”

Narelle

Aunty Trish Levett talked about using the cards as part of healing, to help families move through grief and trauma.

“We are survivors. We have been here for a long, long time. We are always fighting a system, especially our health system, to move forward, to make things right for our mob.”

Aunty Trish’s card was “survivor”
Galambila CEO Kristine Garrett provided a video introduction to the service on the mid north coast, and the importance of reducing smoking rates.

The creativity and talents of local people are a starring feature of the dynamic Ready Mob team’s work in health promotion and tackling smoking.

Another feature of the team’s work is the importance placed upon building trusting, respectful relationships with community, Kristy Pursch and David Read told the Forum.

Kristy and David also described the importance of social media to their work, in enabling community engagement and the creative development and sharing of health promotion messages.

David talked about the importance of building trust when working with the Bowraville community, who had been traumatised by the murders of local children, and experienced short-term responses by a plethora of services.

“We had to build trust to work with that community. It meant that we had to keep our word, be honest and transparent, and everything we did was from a community base. That involved Elders and community in planning events. Not announcing the plan, but starting with the community, ‘let’s do this together’. Out of that came the Bowraville Memorial Cup.”

David Read
This was a touch footy competition held in association with a youth expo involving 20 services. It brought young people from many communities together and they played on teams that mixed up people from different schools and areas. This year, more than 1,000 players from 11 schools are expected to register.

David said these activities were important for developing relationships and collaborations, and in providing a platform for health-related messages and interventions.

In working with young people around smoking, David said Ready Mob takes a “deep approach” that addresses issues such as intergenerational trauma, rather than just saying “don’t smoke, it’s bad”.

“We talk about how smoking was introduced to mob through rations, we talk about intergenerational trauma, and identity. This is what we are finding is working. This approach has more impact than just discussing the negative effects.”

David Read

In working with people on their quit smoking journeys, Kristy described the importance of being flexible in order to meet peoples’ needs.

Ready Mob received some funding from a local health district to buy nicotine replacement therapy, to enable the team to do education and training about how to use these products successfully.

“We really want to take our clients alongside us; we want to walk alongside them on their journey and not just tell them what to do but actually to find out what is going to work best for them.”

Kristy Pursch
The Ready Mob team works with local people in developing advertisements and campaigns for social media and mainstream media. One post on Facebook made by young people in Kempsey reached 17,000 people.

“We identify our local people and local places so it’s relatable to our communities, so people understand it’s mob talking to mob. It could be their family members or a really well known aunty or uncle sharing these messages.”

Kristy Pursch

One of their latest campaigns, Butt Out Kids, was filmed in Aboriginal preschools in Kempsey and Coffs Harbour.

“We were able to utilise our own young people from community and aunties who work in there, and singing in language, it was a fantastic campaign that went onto commercial television.”

Kristy Pursch

The Ready Mob team creates smoke free stickers for cars and homes, and also works with sporting fields and teams to create smoke free sports grounds and health messaging during events. More than 900 people have signed pledges to provide smoke-free environments for children.
The team also profiled their work with super-heroes and super-baddies in engaging young children in messages about smoking and health. Deadly Dan is a primary school program that aims to prevent the uptake of smoking by young children.

Kristy said this was part of their strategy of being entertaining “because people learn when they are having fun”.

“It’s amazing how well humour helps to get your message across.”

Kristy Pursch

The team is careful never to shame smokers, and to ensure there are safe spaces for them.

“We have designated smoking signs. We acknowledge our mob do smoke; we don’t want to treat them poorly, so we like to create a safe space for people because we can put encouraging messaging around that space. It’s an opportunity to engage with people while they are comfortable and feeling safe.”

Kristy Pursch

Evaluations show the team is having an impact.

The Ready Mob website has a wealth of resources that the team wants to share with other services. They are also keen to share their commercials and to create packages that can be delivered nationwide.
“We love the collective voice; we think there is strength in numbers. When our organisations work together, it’s going to create a much stronger, more cohesive approach.”

**Kristy Pursch**

Watch the interview below:

[https://www.youtube.com/watch?v=Zw_vDpC5c4o](https://www.youtube.com/watch?v=Zw_vDpC5c4o)

Waminda: Caring for women and their families

The Waminda South Coast Women’s Health Centre provides a culturally safe and welcoming space for women and their families in the Shoalhaven region.

Trish and Emma described the range of programs available, including fitness, quit smoking and other prevention activities, pamper days, and cancer screening, care and support.

“We are a very holistic service. At Waminda there is NO wrong door, we provide a community hub/one-stop shop that is a welcoming and safe space.”

Trish

Trish presented data showing that in 2017, Waminda provided 14 pamper days at seven different communities, leading to 70 cervical screens, 598 STI screens, and 194 HbA1c tests for diabetes.

She said the pamper days were very popular, with 20-30 women attending each one, gaining access to health checks and health information, as well as beauty therapy provided by local Aboriginal women.

“All they hear is they are going to get pampered so they come along,” she said.

Waminda is also producing videos about local people’s cancer journeys,
to increase awareness and understanding about prevention, treatment and support, and about the availability of services.

The Forum saw extracts from a video featuring a young woman with cervical cancer encouraging screening and conversations – “letting the family and the community in on the journey so we can support one another”.

Waminda is also developing a journal and a diary to support the journeys of people with cancer.

Tackling Indigenous Smoking (TIS) activities include brief interventions, motivational interviewing, smokerlyzer readings, and nicotine replacement therapy.

“As Trish was saying, we are a holistic service. So we cater for women whatever journey they might be on. With the TIS program, we encourage women to reduce smoking levels and achieve better outcomes. We provide opportunistic support wherever the client is on their journey.”

Emma

Emma said the Waminda fitness group won the Knock Out Challenge last year and invested the $20,000 prize back into community services and activities.

“For more information: http://www.waminda.org.au/”

Emma

NSW Aboriginal State-wide Cancer Forum – #AHRMCCancerForum
Yerin Incorporating Eleanor Duncan Aboriginal Health Centre.

Kylie Wheeler and Maddie presented about their work on the central coast, including the recent establishment of the first smoking cessation group.

Kylie said they already had 147 members on their anti-smoking Facebook group, and had developed their own local branding and symbols.

They also had developed a tobacco trigger diary in which people could identify the factors associated with their smoking and what distraction strategies worked for them.

Kylie spoke of the importance of close relationships with local health providers, including a chemist who provided NRT sample packs, and with the Primary Health Network and Local Health District.

The centre also has a focus on cervical cancer screening and increasing breast cancer screening rates. Health promotion activities included pamper days.

Kylie said she found the Forum a useful source of ideas.

“Ready Mob, I am just in awe; I want to come for a visit and pinch your ideas.”

Kylie Wheeler
Focus on social media

The uses of social media for advocacy, community engagement, health promotion, and cancer support activities were profiled during a workshop.

Professor Bronwyn Carlson from Macquarie University, who has previously worked at the Illawarra AMS, presented findings from research undertaken with her colleague Ryan Frazer, Social Media Mob: Being Indigenous Online.

Professor Carlson said the two main platforms used by Aboriginal and Torres Strait Islander people were Facebook for cultural and social engagement, and Twitter generally was more for political engagement.

Her research found that 73% of participants believed social media helped them express their Aboriginal and/or Torres Strait Islander identity, and that 81% felt a sense of being part of an Aboriginal and/or Torres Strait Islander community online.

Social media also provides new pathways to enable help-seeking – for health, employment, housing, economic opportunities, legal services etc.

Racism and trolling online are pervasive, and Professor Carlson’s research found that “social media is not a neutral or necessarily safe space for Indigenous peoples”.

Professor Carlson said further research was needed into cultural aspects of social media use.

“How are we engaging with our own cultural protocols in online spaces which are now an extension of our lives? How is it that we teach our young people about cultural protocols online? How do we transfer those cultural protocols that we have and we know into online spaces, so we can take care of each other and take care of young people, so we know they are acting in a culturally appropriate manner? How do we build capacity in a cultural way in online spaces?”

Professor Bronwyn Carlson
Professor Carlson presented a case study of Facebook being used to support a family and community through the cancer journey and death of a well-known local woman, including through fund-raising.

Facebook was used to bring the community together, and to let people know when it was OK to approach the family, and to stay connected with them and provide support in the years after her death.

Melissa Sweet and Mitchell Ward from Croakey presented on the value of Twitter and the importance of design when producing social media content.

Melissa said Twitter could be used for advocacy and challenging mainstream narratives, listening and learning, developing networks, connections and relationships, and breaking down silos.
Wrap Up

Participants said the Forum had been a “massive eye opener” because of the opportunity to learn about what other AMSs are doing around cancer. They spoke of the importance of staying connected, to enable ongoing sharing of resources and ideas.

Participants stressed the importance of respecting men’s business and women’s business in cancer-related activities, and the need for a greater focus on men’s health.

Discussions also highlighted disparities within the sector; some communities have access to far more services and support than others. Lack of access to transport services was a particular concern. The difficulty of funding NRT was highlighted.

Participants spoke of the need for support for the implementation of local and collective social media strategies and activities. Building workforce capacity in communications and grant writing was another priority.

Professor Gail Garvey stressed the importance of constantly maintaining a focus on cancer.

“When I first started doing research in cancer, there were a lot of people in community and primary health care who didn’t want to talk about cancer, so having more and more people talk about cancer like this group is very encouraging. But we have to continue the support and continue the conversation. We need to keep it constantly on the agenda.”

Professor Gail Garvey

Dhinawan Baker closed the Forum by highlighting the importance of self care for those working hard for their communities in ACCHOs.

“Future generations will benefit from your work,”

Dhinawan Baker
Sharing stories of success, strengths and need

NSW Aboriginal State-wide Cancer Forum – #AHRMCancerForum

The #AHRMCancerforum Influencers

The Numbers

4.816M Impressions
620 Retweets
102 Participants
4 Panelists
6 Speakers

#AHRMCancerforum Participants

Data for #AHRMCancerforum can be up to 10 minutes delayed
Selfies and Snaps
Selfies and Snaps

This publication was produced for the AHMRC by Croakey Professional Services (Melissa Sweet and Mitchell Ward).