

Caring for Our Community – Working with Aboriginal and Torres Strait Islander health workers in providing cancer care training

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Breakout Room 1: Friday 15 June 1100-1500

Patricia Kennedy: Welcome and thank you everyone. Rachel has just joined us, so thank you. Got me working, night and day. Welcome everyone to this session after morning tea. I'm on the board of Health Consumers Queensland. And in my day job I work for the Heart Foundation but enough about me, I would like to acknowledge the traditional owners of the land on which we're gathered and my respects to past present and emerging. We have some speakers to talk about their journey in caring for our community and I'm going to be telling you a bit more about how we engage Aboriginal health workers. So I'll welcome the Cancer Council to talk to you.

APPLAUSE

Sherryn Davies: Thank you, my name is Sherryn Davies and I'm the cancer education manager at Cancer Council Queensland. I'd like to introduce Patricia as well. Firstly I'd like to acknowledge the traditional owners of the land on which we meet today. Last time I saw Rachel except for in the street, I've been in a community meeting and broke my leg and I became a consumer that day straight after being a community board advisory group. That was interesting day. So we're here to talk today about a program called caring for our community I with which focuses on providing cancer information and end of life information to Aboriginal and Torres Strait Islander health workers. There's so many people who provide support to Aboriginal and Torres Strait Islander people but there's also more that people can be doing to provide support to Aboriginal and Torres Strait Islander people. We know that Aboriginal and Torres Strait Islander health workers play a critical role in providing health care and support in their community so this is not just people with that title, health workers, Aboriginal and Torres Strait Islander health workers, this is the broad definition that we're using today of Aboriginal and Torres Strait Islander health workers. We also know that they act has very important advocates and provide invaluable information and support to Aboriginal and Torres Strait Islander people going through the

cancer journey, their family, friends, workplaces. Mortality rate is higher in the Aboriginal and Torres Strait Islander people than non-indigenous Australians. This is the same for a lot of health conditions as well. A couple of years ago we provided a cancer basics course for Aboriginal and Torres Strait Islander health workers which went reasonably well, but really as an organisation we hadn't provided any additional support for Aboriginal and Torres Strait Islander health workers or Aboriginal and Torres Strait Islander people themselves since that course. We received a cancer Australia grant which I'll acknowledge that the end of this session to provide health worker cancer and end of life training to Aboriginal and Torres Strait Islander health workers. I ended up getting the project management of that as a bit of a surprise within my role.

We do have some resources that are available to Aboriginal and Torres Strait Islander people but we know we have a lot more work to do. We're only in that very early stage of providing good information for Aboriginal and Torres Strait Islander people.

The other thing is that breast cancer network Australia have a fantastic cancer diary and we saw one of those movie clips about the guy saying to write down your questions. Has Cancer Council thought about doing a cancer journey diary available for everybody or is it got to be specific to the different...

Cancer Council Queensland and across Australia work for all cancers. If there's a resource done by breast cancer that is a really great resource we will refer the organisation, we will refer people to access that. So we're trying to look at the gaps in services and gaps in information, so if there's things that exist we refer people to those but I understand your question and at the moment there's not that specific broad scale information that would go to everyone, but we can talk people through that journey in the question it's people ask through our counselling service and our NHS counsellor service, also our 131120 line. It can be done on that individual level about providing guidance to the person about what kind of questions you ask, this is the kind of experience you'll come across and guide people but we don't have plans at this stage for a resource to do that and I wanted to quickly touch on what your question was before or your statement was before that we have counselling services available on our phone line which is available for bereavement as well and palliative care, so I'd encourage you, if you're interested to contact... Through 1311 20 for cancer anything including palliative care and bereavement and our palliative care assist program is all health conditions so I'd encourage you if you're interested you can seek some support through Cancer Council.

Audience Member: That's OK, uce is short for sis. I'm glad I came because that interview helped me in a way where I was open and I've never really done that anybody... So no... Thank you!

Sherryn: You can see for us being a community organisation we also understand our position and the limitations that even we have as old elders of the community and how rich it was to have people from the very people we were trying to talk to to share. One of the surprising findings when we talk to them, I remember reading the findings and I was really shocked and really wanted to talk about it and these guys said, "That's not surprising to us." They already know the solutions, the issues, it's just making - giving them a platform for their voice to be heard. We'd just like to end with - the mark of good statecraft is shown in blending idiosyncrasy. He's talking about the how the power of western ontology and our Pasifika ontology can be merged to produce something beautiful for us who have chosen Australia to be our home and it's about blending the idiosyncrasies of our cultural differences allows us to join the best of our non-aligned worlds, to promote Pasifika young people and their families' health and wellbeing. Thank you.

Our second presentation for this session is building QuiVAA and QuiNH. I'd like to welcome Julie, Jennifer and Niki to the stage. Thank you.

Julie: Hi everyone. First of all, we would like to acknowledge the traditional custodians of the land on which we meet today and of the many lands upon which we work and play. We also repay our respect to elders past, present and emerging. Do I need to do something? Expert experience and co-design. Three of us are going to talk today. We haven't practiced it together so try and be patient with us. Niki, would you like to - that's the one that you press we are all here representing QuiNH and QuiVAA. I'm talk about QuiVAA first. The Queensland Injectors Voice for Advocacy and Action, I have been involved with QuiVAA for five or six years, I'm currently present of the organisation. So QuiVAA is Queensland's peer based drug user organisation so basically what that means is we are run by and for people who use drugs. So we're owned and operated by people who identify as people who use substances, what do we do? We do a fair bit of advocacy around things like drug law reform, and drug policy, we do this sort of stuff, representation and ensuring the voice of people who use drugs across Queensland is heard in a whole variety of forums. Sitting on lots of committees, things like that but ultimately we work towards the health and human rights of people who use drugs across Queensland. We

work very closely with QuiNH, the Queensland Injectors Health Network and we're based in the same office in Bowen Hill, to QuiNH I guess is the service delivery organisation so QuiNH provides a whole range of health services to people who use drugs. For example, needle and syringe program, counselling, psycho educational groups, outreach, case management, we have a medical clinic, that kind of stuff and we have sites across Queensland. And QuiNH has sites across Queensland so Cairns, Townsville, Sunshine Coast, Gold Coast, Capalaba and us in Brisbane, we are here today to talk about engaging people who use drugs. I think on top of all the usual important factors thatst that we consider when we engage consumers of health services there's a whole other layer or specific considerations to take into account when working with people who use drugs. One of the main factors is the stigma surrounding substance use particularly Ellisits substance use and particularly injecting illicit substances, people who inject drugs are some of the most stigmatised people, and stigma is one of the most - research shows it's one of the most significant barriers for people who use drugs in accessing health service, that's where people who use drugs experience the most stigma and discrimination in health services that are supposed to be there to support them. Drug use is criminalised and I think that's the main reason, we don't view drug use as a health issue or a human rights issue, we deal with it by criminalising it and so engaging people who use drugs, that's a huge risk in the first instance when wanting to look at engaging someone who has experience with drug use, you're asking them to identify as someone who breaks the law essentially and there are huge implications for that long-term, affecting employment and family and a whole range of opportunities. There's lack of understanding from workers and the sector in general around how to engage people who use drugs, often it's just put in the too hard basket or people are too hard to engage or they don't want to and I think there's all the usual things like an us and them attitude, drug and alcohol professionals as experts, and all that I guess comes from stigma surrounding who and what people who use drugs are. Engagement isn't really embedded in the drug and alcohol sector. We still have a long way to go. There's a real lack of funding opportunities, there's very limited peer opportunities and consumer roles for people who use substances across the drug and alcohol sector and beyond unfortunately. F the language that we use to talk about people who use substances is a major issue, a lot of language that is currently used is often mental health sector based language and it often doesn't fit for the drug and alcohol sector. There's still a lot of places that use really stigmatising language such as drug abuse, abuser, addict, viewing drug use as a disease.

Audience Member: Last question. I'm Louise from the Health Consumers Queensland collaborative. I'm from Cairns. I want to know about Cape York. In the health worker courses, because you brought up treatment, intervention, screening and end of life, was there anything brought up for the wellbeing of the families in those remote communities when one of the family members had left for treatment because that's affected that family wellbeing as well, was there anything in those sources to deal with families left behind because in the communities cancer is death.

Julie: Not directly, but we did talk about the impact of family and communities but not so much about how to support those people left behind except for contacting us to access our services. There was a little bit but not as much as what you're hoping for but just to touch on that peninsula area, the islands up the top, we did have a number of people as health workers who wanted to attend the course, so for some people we were able to provide the bursary which was up to \$700 but unfortunately that also was not enough for a lot of people to attend as well. We could only support so much and our feedback back to cancer Australia because we asked for those really regional areas - remote areas, can we increase the bursary? Unfortunately we weren't able to do that so one of our recommendations back to our funding body was we needed flexibility for those really rural hard to reach areas to be able to up the...

Sherryn: I want to thank all of our presenters as well as you as an audience. You've been very engaged so I hope you have a lot out of the session and I'm sure presenters will be around over lunch.

SPEAKER: We provided all resources that we found relating to Aboriginal and Torres Strait Islander health relating to this course and provided that to participants as well.

Audience Member: If you're 4G about end of life with people who are at end of life how are you managing that process of taking a video of someone's life and how long that video gets used.

SPEAKER: Can we hold the questions to the end?

Julie: The other things that we needed to consider was course locations and it was maybe looking at where were the places that we could put - set up these sessions that would be - have equity to all of our health workers throughout the State? Sherryn will talk about where they were set up. We all had to look at all the presenters, had to look at the you're having presentations about women's business, we needed a female to be doing that presentation. Also from a male perspective, so we were making sure that we were culturally appropriate at all times. Promotional strategies, Sherryn can talk about that. And the pilot, but basically I wanted to mention to involve you need to be involving many people and the wider group because you need everyone's input and it's very important that you look at who is within your area of expertise and then just - who are the individuals that sit in positions that may be of assistance to you.

SPEAKER: A couple of things about the first and the last dot point around course locations, we try to get as regional possible to go to Aboriginal and Torres Strait Islander people, because previously with our cancer basics course once we'd finished and evaluated that we asked people whether they wanted to go to metropolitan areas in the regions - sorry regional areas or bring that down to more Community level and the thought was taking people to the - the feedback we received was taking them to the major centres so people could see as held workers the patient journey in action. We had site visits that people could go to the hospital, see what treatment facilities exist and preventative screening as well and we had an application and bursary process where we were very thankful to cancer Australia gave us money to support people to attend the sessions, we had up to \$700 per person to attend. That was a really useful experience, some of the feedback we received was people didn't understand what bursary meant so we changed the language around financial assistance and things like that. It was all very valuable feedback.

This is just a quick snapshot as to where we held our course, Napranum is just up around Weipa. We really did get out to community. Just the course participants there, Cairns had significantly higher attendance than everyone else, but there was also a lot of reasons why people couldn't attend. Some of that was workforce issues out in the regions, they couldn't have people off two days but if they're travelling could be four or five days from regional areas, there was a major weather event in Mount Isa so we had to change the date of that course to just prior to project end date which caused some stress but it was a good thing because it allowed to us continue engagement with the Mount Isa

community but there was a lot of workforce issues that stopped people from attending.

The outcomes, we had 108 people attend, at least 959 identified as Aboriginal and/or Torres Strait Islander and the remaining people either didn't tell us what their identity was which was totally OK or we didn't capture it for some reason or another. We had for example of the type of people who attended 31 Aboriginal and Torres Strait Islander health workers attend, 14 indigenous liaison officer, seven personal carers and a lot of other people who attended well. We established nine cancer networks which anyhow that the project is over we're now focussing on how we continue to support the people who attended and also the advisory group members and 154 people involved in the project as well. We had those advisory groups. I'm pleased with the evaluation we received. Every single participant valued the cultural considerations embedded into the course. They've all gained knowledge and confidence around cancer care and end of life. They're more informed and all committed to take the information back to their communities whether that be their family, their self, their workplaces or community on a larger base, 100% of participants rated the content of the courses as being appropriate and 100% felt culturally safe and welcomed.

That's why I was saying before I feel incredibly proud of the work that we did not just as Cancer Council but every other person who participated in the course because that was the most important thing for us. After the course over 90% of participants reported that they better understood their role as health professionals in supporting people in the cancer care space and end of life space. Pat will run through a couple of the highlighting quotes that we received.

SPEAKER: This is just some feedback. I have learned more about Aboriginal and Torres Strait Islander health in these two days than I did in my entire health degree where I had one elective. The course needs to be ongoing to all communities to deliver so our people have more understanding and knowledge to feel assured that they have all the support and not to worry. I feel I can make a difference in helping my people and family. I now feel like I can talk with my patients and hope to give them a lot of information as they need. Hold this course regularly for any new information and for the younger generation that will come on board as a health worker. I found this information that I have learn about has given me an open mind about people with cancer, what they go through and the excellent services available for them to help and support them through their journey.

SPEAKER: In addition to the course participants learning a lot out of this process, Cancer Council Queensland has too, we need to keep working in this space to look at all of our services across Cancer Council Queensland and not just this education session. We now feel more confident in working with Aboriginal and Torres Strait Islander communities and services. We feel more informed about how to provide culturally supportive practice and we feel more connected to our communities not just in Brisbane but throughout all of Queensland. We feel as though we're better able to support Aboriginal and Torres Strait Islander people who access our service but also through - in our future work around looking at all of our other services as well. We really enjoyed the courses because there was a little bit of anxiety about doing this project but everyone who delivered it from a Cancer Council Queensland perspective really enjoyed it, really enjoying the yarning, the learning the sense of community that the advisory group members brought to the project. We've since been invited to Aboriginal and Torres Strait Islander events and with NAIDOC coming up had quite a few invitations and things like that which we didn't have previously, we've increased our reach and access of services, we all want to continue enhancing the services we provide. Just some recommendations, plenty but I've just pulled out a couple.

Warning statements. The content or the individuals you've been talking to may have passed on so you really need to be put that statement in front of everything. That is respecting the community that you're talking to and past and present family members. Language images and stories, we all need from an Aboriginal and Torres Strait Islander perspective, we need to see our own stories up there. What makes us look at from our own perspective is to see that language, to see the images and the stories. The content, knowledge and gaps, you need to be looking at that, importantly, because not everything fits everyone. This is very important with an advisory group. Yarning sessions, from an Aboriginal and Torres Strait Islander perspective you need time to talk about things, to sit and discuss and that's why yarning sessions were very important as part of the training. Services and resources...

I became a drug and alcohol counsellor. Really proud to take over this project. Really lucky to have Niki on board, a lot of consumer reps that we have recruited have come from a group that Niki runs called mud maps. I just pinched your bit. Do you want me to run with it?

Niki: We're not on drugs!

SPEAKER: Not much. QuiVAA receives some funding for a project officer 16 hours a week and this is the awesome Julie. Julie - her role is to - I guess the aims of the project are to engage consumers and peers of both QuiNH and QuiVAA. People who use substances in organisational engagement opportunities and also opportunities throughout the drug and alcohol sector. We want to build the capacity of people who use drugs to be involved in the decisions that affect our lives and have a connection to us and to their peers and community. It is a peer and consumer-led project, we're all here because we identified a people who use substances so we are peers and we have or have been consumers of health services ourselves, we have a steering committee, with our consumers on it leading and providing strategic direction to the overall project and the training that we are developing is consumer-informed and consumers are involved in every aspect of QuiVAA's project and a big part of that has been our organisational readiness, where are we in terms of our ability and capability to do this? We really started - we had to start with really where are we at, we want to work towards embedding. We're not always lucky enough to have a consumer engagement coordinator so this stuff needs to be embedded in all levels of organisations if we're going to do it effectively and sustainably.

SPEAKER: I've written up there stages of the project, because we're really on the hop. When I first came into do the project it looked really different with the agreement that we had it was about recruiting peers and talking about volunteers and getting peers to be workers and then I came in and thought "alright start recruiting" and got the whole recruiting things happening and better have a look at the foundation first, have a look for policies and procedures and I couldn't find anything, then I went back and had to start writing - I wrote a policy on it and then thought "wow, steering committee." Put it together with the termses of reference, had to do lots - the reason I'm telling you all this is because we went "this is not safe, we need to build something y that's really strong and call it consumer engagement and participation before we even start talking about peers." So. We then - I started doing all of that ground work, all the foundation and then went "I'm not doing this right, this is not informed by the consumers," then we set up the steering committee. We have two consumers on it, we have 25 expressions of interest for people who want to be consumer reps with QuiNH which is fantastic, they're a great crew. Then we sort of went back to the audit and thought how are we going to audit. We went around and asked question, how ready do you think we are? We're fantastic, we're ready, bring them in and then we thought so they're going to be wandering around in here, how do you

feel about that? Not too sure about that. Then we did an audit and while we found that people who work with QuiNH were really keen to have this happening, they weren't ready and they didn't have knowledge of what we were speaking about, they didn't understand consumer engagement and participation so it was like back to the drawing board again and we were recreating the actual agreement. We did the position description for the consumer reps, we did a remuneration policy, we pay our consumers cash. I think that we all have difficulty if we're giving them a food voucher, what we're saying is we don't really trust you, we're going to give you a food voucher so you'll get food because we don't think you should buy drugs, cash is cash man, if they want to buy drugs, that's their business and who says they're going to anyway.

Anticipated opportunities. I guess we're looking - five minutes - the kind of opportunities that we're looking at is we want to build a pool of consumer reps, I'm Vic does a really good thing together, a group called speaking prospectively. They have a pool of consumers like Health Consumers Queensland does, and we are putting training package together to train everyone but we're also putting a training package together for our workers and we had a focus group on that, we had six consumers come in and we said asked them questions like, "What would you want people to know? And how do you feel about this?" We got some great feedback and the training package is going to be built around that but the training package will also be built around the feedback for the staff who believe they're really ready for it but really aren't. The kind - it's gone again.

The kind of barriers that we're coming up against, we've had some difficulty engaging Aboriginal and Torres Strait Islander people, we've had difficulties engaging youth, the LGBTI community not a problem, we're doing fantastic there, we have a really good crew on board. As resource paucity, we're really low on resource, getting the word out, was a little bit difficult but not that difficult, mud maps was great. The big thing is lack of evidence from other alcohol and other drug agencies who have been through this same process. I think that we just might be the first who have started from the bottom up and put the whole consumer engagement and participation program together which is kind of like not what we started out to do but it's pretty beautiful and there's the staff manager.

The best person is the consumer or the patient. If I have a knowledge of those things being available then I can refer people to it so I think - I think - I don't think it should replace or try and reinvent those other processes that are flawed, I think almost the opposite that it can assist

those and is effectively a double check and ensuring that we as consumers have more visible and that it's connected as well.

SPEAKER: Thank you. One last very quick question, we're almost out of time. Suzanne?

Audience Member: Hello. I think it makes perfect sense to digitalise the health record but the one area of concern is the secondary use of patient data. And I read that from 2020 identifiable medical info will be available to third parties and although it should be in the public interest it also said it can't be used solely for commercial purposes, I found the word 'solely' a bit worrying, also it should be identifiable when for most research purposes it doesn't need to be and I also understand that arch two years it will be up for review with the possibility of wider uses including provision of data to insurance agencies, after the opt out date, especially after two years have gone by and all the launch fanfare will die down, how will people fully understand where the information might be used, especially if it changes after the review? Thanks.

SPEAKER: I'll respond to that. It's a good question. Prior to the announcement of the opt-out there was also an announcement of the secondary use framework and that's the secondary use data framework for My Health Record data. First call out, all information used for secondary use is de-identified so it's de-identified and also a person can have the ability to have a My Health Record and then opt out of their data being used for secondary use purposes so that's the important thing to kind of specify, it's not I'd official, it's de-identifiable data. Secondly it will come in in two years and there's a clear governance process around requests for that information. Insurance companies cannot access that information, that's been called out in the framework from the Department of Health and any requests for information i.e. medical research will go through a committee that will include consumers on the committee, representatives from a range of different groups in the community and ensure that there is a clear and transparent robust process on why they want to use the information.

In relation to the consumer opting into the secondary use of data if you choose I don't want my information to be used and you change your mind in the future you can then include your information into the future, as Matthew called out around personal choice and control, it's the same with the secondary use framework. We'll be here if there's any other

questions we can address those but I think we need to wrap up for lunch.