

Day 2 – Q&A Concurrent Session 1

Facilitated by Dr Erin Evans, Health Consumers Queensland Board

Bridging cultural barriers: Designing breast screening health literacy resources through consumer engagement

BreastScreen Queensland Northside Service

- **Anna Voloschenko, Project Officer**
- **Rose Carlo, Consumer Representative**

Words for wellbeing: A partnership approach to improving community health literacy

Redland Hospital, Metro South Hospital and Health Service

- **Kim Guerrara, Librarian**
- **Monique Whitewood, Team Leader, Community Program**

Audience member: Hi, thank you all for your work. My question is about the Words for Wellbeing group that you have that were deciding which books. Does that include consumer representatives? Are you having people giving input on really how readable and how relatable this is for new clients, or is it just medical professionals that are looking at it?

Words for Wellbeing team member: The thing is the books are recommended by health professionals so that's more the health professional that's recommending the books. However, we certainly welcome any recommendation by a consumer, because then we take that recommendation and we pass it on to a health professional to look at, as well. That's what we're doing at the moment with the Redland Dementia Alliance. I'm getting the list of books that the consumers and the carers have said really helped them and then I'm taking them back to our dementia unit and getting some of the doctors and nurses to read

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

through those books and also give their endorsement and once they do, they get put on the list.

Audience member: I wanted to ask Anna and Rose, I was really struck by that slide where you talked about the fear of governments and how people from CALD communities may have a different view of government than many of us do. Particularly I would presume for refugee families coming from countries where the government was an agency of strife and terror and difficulty. I wonder, what is the role of the husbands in the family if they receive a letter that is from the government about something that they should or would like them to do. I wonder if there's a need there to educate the fathers and the husbands about how they can support this change, as well?

Anna Voloschenko: It's so hard to see the audience, it's a bit like the theatre here. You're in the light, but you can't see where the question's coming from. Now I will answer this question first and then I'll give it to Rose so she can put her perspective on to it. It's unlike in the Aboriginal communities where there is women's business and men's business and you'll find some of those kind of issues are perhaps discussed, but they are not the major topic ever. So when the letter comes into the house, depending on who it is addressed to, but in this case it will be addressed to the lady of the house which means that the men might never see it. It's a similar situation with the cervical screening as well and that's very much a women's business as well so it's very hard to do that. But I see your point, in what would happen if the husbands support that? I'm sure they do, it's just they don't know what it is. I was really very, very surprised that there is no word that's described in the dictionary for breast screen and therefore, most men would know that there are tests and things that women do. But from other areas, I guess as far as support goes, it's difficult. But it was really very interesting for us to find out there was so many comments about the letters. We never thought that and those of you who are in the process of writing letters, make sure that some of those things are taken care of. Who you're sending it to and what's the purpose of it? And then, the actual writing is something that's understood, because if it's full of jargon people will not understand and one of the things that we are finding is there have been changes to cervical screening program, but also what's happening is that children... well "children" I'd say in high school, the kids are

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

vaccinated against the HPV virus and what happens is many people don't know what it is and if our community is about 60 per cent of us are illiterate, just imagine how illiterate the other folk must be. We've been asked questions during focus grouping stuff for the actual brochure and for the booklet. What are these letters? What are they all about? Is it important? And we say "Certainly it is", and some of the feedback from the doctors we got was that suddenly they got an influx of people who brought their daughters and wanted them to be vaccinated. So they didn't know what it was, the letter from the school asking their permission and they had to sign it and all of that and consequently what happened was they didn't know what it was so they again threw it in the bin. I don't know what views Rose might have about men assisting to the breast screen, but if you're going to do that folks, it's an all-women's service. He might have to wait outside and get himself a paper and a cup of coffee.

Rose Karlo: Hi, my name is Rose and I'm a refugee from south Sudan and so I came late. It's not African time, I swear, I just got lost around here. So with regard to that answer, me being a south Sudanese, 90 per cent of the population is illiterate, so literacy is quite a big issue. Although especially the health practitioners at the hospitals you see, they speak English. Sometimes they just say "yes" to please you, just to go to get on, to get help, or it's the process or procedure just to finish and see what's the end result. That's another thing and the refugee communities, we have many languages and there is quite a challenge in when you are asked "What is your main language?" Because if you ask me what is my main language for example, my mum is from a different tribe group, my dad is from different group, my step dad is from a group, but my neighbours are from a different group and we have like five. And then we have our main language forced on us, either English or Arabic. So sometimes I get confused. I will now Arabic, if you ask, what is your main language, they'll be like "I studied English, English". A lot of men have no English. Not just men, women. Women's business in African culture, when it's about breasts or something like that, they will be "No, I've got nothing to do with that" and with a lot of refugees too, you see most of the percentage, up to 60, or over 60 is women at risk that come here. So there are lots of single mums who have no husbands to answer your questions.

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

Audience member: My question is about the Words of Wellbeing. Other local authorities have you spoken to them at all about implementing a similar scheme? I'm from the Gold Coast and I haven't heard of anything down there along that way?

Words for Wellbeing team member: So the program at the moment is Ipswich and Redlands. I would recommend lobbying your local library is the answer to that one. No one else has picked up the program as yet, but there's no reason that they don't or they couldn't, so it's a matter of if you are in a different council, start lobbying.

Audience member: Yeah, I didn't want them to reinvent the wheel.

Words for Wellbeing team member: The program already exists and there is recommendations of books and resources available. So for them, we've even tapped into the same marketing that Ipswich have, so it's quite a simple thing for them to pick up if they have the drive and the ability to do so.

Audience member: I hope they have, thank you.

Audience member: I'd like to ask Anna a question, please. We've been talking about women's breast health. What about the men? We know that the men do have problems with breast cancer, so do they have, or is there a regular program where men can go? Or is it just through the GP if they find something in their breast?

Anna Voloschenko: The actual numbers of men who do get breast cancer is small. It's somewhere in the vicinity between 5-10 per cent, but it does happen. There are support groups available for that sort of support for men and there are brochures that are being developed. I would personally like to see something similar happen, like we've done with our women's breast brochure or some kind of information. But through some of the programs that have been done through the Ethnic Communities Council we find whenever there is a health program, men just don't come. Men normally unless it's something that's of interest to them, if it's to do with health, they prefer to leave it to their wives or their girlfriends. But in CALD communities it's probably even more pronounced. It's not

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

something which they like to be involved in, because they also know that when they come to a group it will be mostly women and that will make them feel uncomfortable. But going back to your question, yes, it's something that is being looked at but because of the small percentage of men, it's not being publicised hugely. In men also too, the recognition of breast cancer is a lot easier because there will be a lump that would be pronounced in those men I guess who have relatively... how shall I put it without offending anyone? Flat chests, so it's something they can see. In women obviously it's a lot more difficult, but we do recognise that men do get it and it can be a very difficult treatment to start. But yes, it's being looked at.

Audience member: My name is Danijela and would you say there is enough reason to actually start working on a general awareness of prevention for different diseases and illnesses that we have in Australia, which a lot of developing countries really don't have. In those countries people go to the doctor when they're feeling ill. In Australia, we have a lot of approaches for so many different conditions which people of CALD backgrounds and refugees probably wouldn't even think of, because as I said before, they just go when they are ill.

Anna Voloschenko: It is an excellent question and one of the reasons that prevention is not even thought about in communities from culturally diverse backgrounds is they're just not available in the country of origin. They don't think about it, but also too, one must realise that very often folk in those countries don't live long enough to develop some of those conditions and that's possibly the reason although the main reason would be that the health system is so overburdened with looking after the sick that they just don't simply have the time to do the prevention for the community. But going back to Australia, yes, there should be more prevention programs available throughout not only just Queensland, but everywhere else. Look what happened to smoking. There has been so much promotion of giving it away that we're now down to 16 per cent and when I started in this business there were 62 per cent of men - not just men, but people who smoked. It's down to such a small number now, because it is unacceptable, it is something that people don't do. But you know where it all starts? It starts with the policy. The old charter where it says unless you have a policy that the government is doing something about it, that there

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

is awareness raising within the community and within the hospital systems, it's just not going to happen because people themselves these days are too busy. Health is usually something that is not thought of unless and until they get sick and once they get sick well then, they get treatment. But many of us are perhaps just complacent thinking well, we've been well all this time and there is nothing to say we're going to get sick in the future. But I would be, whoever it was that was asking that question, I would be the first one to jump to try and do something about some of the prevention strategies which are easy enough, but they need to be promoted and people need to be assisted with them and the library as you've heard, is an excellent place to start. If all the libraries had that sort of information, people might be able to avail themselves of the services, because these days books are expensive and when you go to the book shop you don't really know, is it a my learned friended book, or is someone peddling some sort of a program that they want to join? So if there is something that's recommended and it's working hand in hand with the local hospital and the local GPs, it would be absolutely fantastic and I, for one, am going to get in touch with you to see if we can get that booklet going through the library so that may be some of those women who come from culturally diverse backgrounds can read it and can perhaps make an appointment so we can actually see the difference in the screening rates of women. Not just from culturally diverse backgrounds, but maybe from the others, as well.

Audience member: Yes, for me, I always say increase in workforce diversity would be resolving if not improving some of the issues. That's all I can say. There is a great need actually and I think due to limited resources, so there are a lot of challenges and most of the community leaders are really battling to be a go-between, giving the support to their communities involuntary as well as advice to the government or to the services.

Anna Voloschenko: I'd just like to say something, as well, because Rose is a community leader and they run leadership programs for community leaders and as Rose was so involved with the development of the booklet she can now tell you just what resulted out of that booklet and what she has done herself for her health and being healthy for the future. Can you tell them, Rose please?

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

Rose Karlo: Okay, thank you Anna. I wanted to skip that part, that's why... but yeah, after the process I'm really like, I volunteer and I work as a program officer in one of the community engagement teams, so I was really interested to be part of this project so I would be able to promote it to the community. So I thought let me try first and see how it is. At first it was fun and very exciting and everything, so Anna took me, we went up to North Lakes and stuff like that. I live in the south side, so after that, Anna told me that you know after doing, I thought I was just going there for the booklet, for my pictures to be in the booklet, but I'm like "Oh, why not? Let me try have the breast screening and stuff", because some people say it's not comfortable and stuff like that. But when I went through the breast screening my first experience was I went there without even knowing which I suggested to Anna to include in the book that maybe for CALD women you need to tell them what to dress going there, because I wear a dress and I had to take all my dress off and I'm supposed to wear pants or skirt and blouse. That was my learnings. And also, for me actually like it was really normal and there was no uncomfortable pain or something like that I was told. African women, for us pain means like you're having labour or migraine headache. And after that, I was told that after a week or something I may be called back if there is something not right in my breast or something just to confirm. So actually, that happened and I was so excited I'm like yeah, it's the same process, I'll just go there, but in the letter although I read that I would be there 3 hours and stuff, I thought that always they say that and at the end of the day it will be like half an hour and stuff. When I went there, the staff were welcoming me and everything and the doctor explained to me oh my God, that's when I freak out. They said there was something in my right breast and stuff like that. So I immediately went somewhere else and thought I was going to die actually and I really felt like "Why did I volunteer to take my breast screen? Because now it looks like I'll be in trouble." So after some time, I was going through check and check and they had to take a sample from inside my... so to confirm that it's nothing. So I almost like, one time I said I was going to the ladies, I went there and dress up, I wanted to run to go to leave before even finishing. They found me and called me back and said "Rose, where are you going? Please change, we haven't finished." Actually, from that, because they had to take a sample from my breast, I had - you know, our Africans love our party and it was the weekend on Friday so I had to go home so depressed that I stopped going to - all I was thinking was that I was going to die. So on Monday they call me that I should come back,

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TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

they want to tell me what was the result. So I was there the first person to arrive, because I wanted to know what would be happening, so actually it was nothing. It was just I have a fibrosis or something that needs to be... yeah. And yeah actually after that I felt that maybe I need to do my 6-month medical check-up, even I never did Pap smear before. After that, it's good and relieved to know you may go through some experience, and I realise that's the uncomfortable experience, the mental torture through the experience and it's all good.

Anna Voloschenko: Well, thank you Rose. This was sort of something that was I suppose interesting for you to hear. Not only did she take care of the breast screen, but she's also gone to the doctors which she didn't tell you and she also had cholesterol check and everything else and being in the position that she is, she's trusting and knowing the community and it's great to hear that Rose, because your encouragement is going to encourage people, because they will think, why can't I do it?

Rose Karlo: In our culture and community we copy each other. So that's how it goes.

Audience member: In light of what we heard yesterday about the new highlight on health literacy in the national standards, it's really wonderful to hear two fabulous projects about what's been done out in the community to enhance the capacity of our diverse population to actually understand and participate in health promotion and health behaviours. The question I have, though, is there a link between this and My Health Record? How do people in the CALD communities respond to this new thing that's going to be happening and how will they be able to understand their health records and participate in this, as well?

Anna Voloschenko: It is really very difficult, because they don't understand what My Health is and again, as I mentioned in my presentation anything to do with being recorded either on the computer or on a piece of paper causes a tremendous amount of fear and they're also worried about the privacy, just how much of my information is going to be recorded. With trying to say to them that it is important to have some of the

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

information particularly if someone has diabetes or has a condition, a particular condition, it's important that that is recorded so that when the person is unwell suddenly people know what the paramedics or the hospital, the doctors know that this is what it is and they start treatment. But also too, because a lot of the CALD communities don't understand what some of those tests mean they might go to one doctor and have one test and then go to another doctor which is doing exactly the same test so it will reduce duplication. But because the communities move around a lot depending on where their houses are and where their employment is, it's very hard to track them. But trying to explain to them that this is something that is going to be very valuable, it's very difficult and I'm having some discussions with people at the moment to see how we can spread that throughout the community so that they know it's something that's going to be useful. But it's going to take a lot of time in order to try and spread that particular thing through the community.

Audience member: Hello, Anna, this is Odette. Some of the CALD men do not attend any activities, especially activities relating to cancer because of the stereotype and the stigma attached and you're aware that education and health literacy playing a big part in this. My question is how we can get the media to deliver the message in more cultural competent way? In the time being, all that we have is 4EB radio for CALD communities, but I'm actually looking at the bigger picture which is the other media channels. Thank you.

Anna Voloschenko: Well 4EB is an excellent source, because they have 101 languages in which they broadcast. The thing is to be able to convince the broadcasters to actually broadcast health messages, because for quite a few people, 4EB and that particular program is the only way that they can get information about anything that's happening in the country or anywhere else. So very often they just simply haven't got the time to do it. I've done some fillers, when there is a bit of a break in the transmission or between programs they can play a particular message for about a minute or two, but that didn't quite work out. I guess you know, from the point of view of mainstream media, we're looking at trying to get some of those health messages across to everyone. But if you actually look at some of the advertisements and health promotion-type messages there aren't many of them at the moment. Most of them are advertisements about food, but is it a good food or is it junk food? They may have a certain amount of advertising a little bit

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

about things like exercise maybe, but apart from that, it's very difficult because most of these advertisements need to be paid advertisements. That's how they exist and if you don't have the money to pay for that, it is very challenging to try and spread this particular news. I don't know what's going on, on social media whether indeed they do have some positive messages, because that would be a good vehicle for that. But I'm just not sure if there is anything useful from the health promotion or disease prevention point of view. But other than that Odette I'm with you, in that it would be good if we could do that, but convincing the media to do it as a community service is an extremely challenging thing to do.

Audience member: Good afternoon, Rose and Anna. I'm here from Cairns in Far North Queensland and I'm the manager of the Settlement Services provider up there. Can I just commend you on the creation of this document, because we are so desperately in need of these sorts of materials for our CALD communities. So, well done. It is much appreciated. We're at the other end of the State so we don't have the liberty and access to a lot of the services that CALD communities do here in South East Queensland so it really is of very high value. Just to share with you too as an anecdote I'm also the chair of the Cairns Refugee Health and Well-being Network and at our next meeting our colleagues from BreastScreen Queensland are coming along to talk to us, so thank you very much.

Anna Voloschenko: We do have people throughout the State in the major cities that work with breast screen. It's interesting that many women from culturally diverse backgrounds think those things are in doctor's surgeries or the screening machines are in doctor's surgeries and in hospitals but you know, it's really not the case. Cairns will have a static unit, but also there is a mobile unit that goes around and they usually park around hospitals and women come from far and wide to have their screening done and it's a service that's been going on now for 25 years and it is a very needed service, because some of these women drive for four or five hours just to get their breasts screened through the mobile unit, because it's impossible to put static units in all the different regional areas. For example... I don't know, Texas or Inglewood some of those places normally wouldn't have a service. But because of the mobile services they do, they just come at a certain time. Everyone knows about it, it's advertised widely and it's something that they do

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

appreciate and we hope that it will continue. I think personally the best thing would be if one of those big mobile vans also provided Pap smears, because then it would be killing two birds with one stone I guess and women would probably appreciate it, but it's not happening at the moment.

Dr Erin Evans: Any further questions from the audience? One more. I think we've just got time for this one more question and Reema gets to run through the audience. Get to work, Reema.

Panel member: Keeps her fit.

Dr Erin Evans: She's getting her 10,000 plus steps today.

Audience member: I was just wondering with the Words for Wellbeing you mentioned there was a literacy program people can tap into and learn how to read. How long is that for?

Words for Wellbeing team member: What we're doing at the moment is it's a new program we're developing. We're about to start the pilot beginning of July. So what that program will be is we are training a group of volunteers from our community, so it's a volunteer-based program. Those volunteers will be matched with a learner and we will have all of our community groups in the Redlands aware of the program. That program for the learners, they'll be matched with one of those volunteers so they have similar interests and it can be ongoing forever. As long as the learner wishes to continue and as long as the volunteer is willing. We will look at that program and evaluate it as it goes. We're sure some of our learners will get to the point where they surpass that, but hopefully that will encourage them into more structured learning or give them the confidence to go back and do their qualified, whether they finish high school or whether they go to a TAFE course or whatever they hope to do. So it's a watch this space at the moment, it's a new program. Many, many local libraries run this program already.

TRANSCRIPT

Health Consumers Queensland Annual Forum 2018

Dr Erin Evans: Thanks everyone. But thank you most of all to our wonderful presenters. Please join me in thanking Anna, Rose, Kim and Monique for speaking on having such a rich discussion about health literacy and accessing diverse communities and improving our health literacy. How can we improve as a society if we don't improve with our health literacy? I've been very moved, because I'm involved in the genomics area and I've got very much got new thoughts flickering in terms of genomics and how we improve health literacy in that area. If you didn't get to ask a question or want to have a conversation, I'm sure our speakers would be more than happy to chat with you over lunch. We'll have lunch served outside and then have a look where you want to go next. Thank you very much everybody for a wonderful day and a wonderful conversation.