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PARTNERSHIPS · LEADERSHIP · ENGAGEMENT

Raising health staff awareness about health literacy issues – the impact of a consumer video on staff perceptions of health literacy, Townsville Hospital and Health Service

JULIE CONNOLLY: My name is Julie Connolly and I am one of the directors of Health Consumers Queensland and I am in the privileged position to sit on the board and provide occasionally strategic advice about how the organisation itself is developing over time. It's something I take great pride in and likewise I'm really happy to be standing here in front of you today and having an opportunity to introduce you to our speakers. I will do some introductions. I'm going to be a timekeeper, so I might interrupt. I've had a notice to try and speak slowly that we have some people who would be able to participate more effectively if we kept the space of our conversation at something easily understood, so I welcome at any time when I'm speaking if you want to say "Julie just slow down" let me know. Sometimes when I get nervous or excited I start to talk more quickly and I think that happens to us all, on occasion. Welcome, I'm really glad to see you all. The official part of beginning this session is of course to acknowledge the traditional owners of the country on which we meet today. We've had a welcome to country, but I also think it's important whenever possible if you have an opportunity to stand in front of people to extend that gesture of solidarity to the traditional owners of the country on which we're meeting which is what I'd like to do. Our first session today is entitled Raising Health Staff Awareness about Health Literacy Issues, the impact of a consumer video on staff perceptions of health literacy. We have two presenters. We have Jo Sherring, who's the Clinical Lead for Person Centred Care at Townsville Hospital and Health Service, which I'm reliably informed can be abbreviated to THHS, and we also have Lyn Hinspeter. Lyn was formerly a nurse and he's now retired and has decided to continue her passion for creating amazing partners. We have an excellent model of partnership come to present to us. If you could all welcome Jo and Lyn to the stage, I will hand over to them, thank you. (APPLAUSE).

JO SHERRING: I've been given the opportunity to start this session off. I hope you can all hear me, I will get a little bit more animated as I go. At the moment, I'm a bit nervous. Health staff often believe that they are communicating with patients and their families in a way that can be easily understood, but when you take the time to actually speak to those patients, to their families, you find this is often not the case. I'd like to just tell you a story that might help to illustrate this. It was a boarding school, it was sports day. One of the young lads injured his arm. He came to the health centre and it was fairly obvious that it was probably broken. He was a day student, so his mum was rung to take him to the doctor to get Xrays, et cetera. A couple of days later, he was seen with his mum and brought back to the clinic. Nice plaster on his arm. The health staff said to mum "Oh, so he has broken his arm?” In all seriousness mum turned around and said to the health staff, "Oh no, it was much more serious than that, he actually fractured it". The implication being she did not understand that fracture was the medical term for the layman term break. So this is the sort of thing that can lead to confusion and misunderstanding around health literacy, around knowledge, around health empowerment. Staff truly believe that they are making a difference. They truly believe that they are communicating well, that patients have knowledge and have understanding but as this story illustrates, this can always be confusing. With this in mind, the patient information and health literacy group of the Townsville Hospital decided to make a video to highlight some of these problems around communication, understanding and knowledge for patients and for their families. A video camera was set up and people walking through the hospital were asked if they would be prepared to help make a video to train staff. They were given a card with commonly used words on it and asked to describe in their own words what they thought this meant. The result of this exercise was interesting, and at times surprising. People were also asked what they would like to talk about... sorry, people were also asked, what was it they would like health staff to know and to understand? The results were a video that we are going to show you in a few moments. This video has been shown in a range of contexts from staff orientation, Health Literacy Week and other staff training. Feedback from staff have indicated it opened their eyes, made them consider how they communicate with patients, and their families and considered the assumptions that they make around patient and family understanding when they give information around health.

Video: That's the triage nurse, which is when you come into hospital to emergency, they'll send a triage nurse which will look after you initially in there.

VIDEO BEGINS

NEW SPEAKER: We diagnose emergencies that come in.

NEW SPEAKER: You're observing the patient.

NEW SPEAKER: Noticing something.

NEW SPEAKER: Checking your ops.

NEW SPEAKER: Which is what?

NEW SPEAKER: Blood, heart and all that.

NEW SPEAKER: I feel like I've heard it before, but I don't know what it means.

NEW SPEAKER: Isn't it a clot or something?

NEW SPEAKER: Going to see the doctor or the head nurse.

NEW SPEAKER: Consultant would be a doctor or somebody like that could talk to you about things.

NEW SPEAKER: This is a health professional who will help with your appointments.

NEW SPEAKER: I've heard of it in the hospital, but don't know what it is.

NEW SPEAKER: It takes water out of your body system.

NEW SPEAKER: Titrate... is it a type of chemo?

NEW SPEAKER: It just means that you're getting something delivered via your veins.

NEW SPEAKER: Intravenous drips, getting medicine through.

NEW SPEAKER: When the nursing staff are changing sheets.

NEW SPEAKER: Handover, I think it's when they're doing one handover from one shift or one department to the other.

NEW SPEAKER: Following introductions... I think.

NEW SPEAKER: It means lots of people working together to manage a person's health problem, maybe.

NEW SPEAKER: Sort of chastising.

NEW SPEAKER: I'm going to take a stab in the dark and you say urinary tract infection.

NEW SPEAKER: Analgesic is something you would give for pain relief like Panadol and Nurofen.

NEW SPEAKER: It's something to do with stress relation.

NEW SPEAKER: You answer the questions as you think the patient wants to hear it not what the patient wants to hear and there is a difference.

NEW SPEAKER: For example, my husband had a dyanoma in the aorta and they were talking about all these big words and I'm not a medical person so I wouldn't know what it meant.

NEW SPEAKER: It's all going very quickly and it gets frustrating and confusing, so much so that I've missed about six appointments due to that. I wanted to call up and ring the receptionist and then had to go through it again with me. That's why I'm here now, because I missed an appointment, because I couldn't understand my introductions from my previous doctor.

NEW SPEAKER: Because there's lots of words given to you in a very fast way while you're trying to think about what that word meant and what the implications of that description or that diagnosis is, they're already up here at the next paragraph saying stuff, so yeah, it's delivered too quickly and without enough time to process each part.

NEW SPEAKER: Sometimes I know what the doctors and that are talking about. Some of them are good in plain English. I've spent the last three or four months in here... they explain it pretty well.

NEW SPEAKER: Put it in layman's terms so everyone can understand. Especially if you've got family members there, it's important for everybody to have a level playing field and understand exactly what's going on.

NEW SPEAKER: Because I've missed a couple of serious appointments and I've got to go back to them now, because it wasn't important enough for me to remember, because it wasn't explained to me like that. The doctor says, I can't give you a diagnosis on this today, because you needed that one and that one together, but you've only got that one. So test A was done, but not test B, so she couldn't get a clear picture on that alien in my neck, because she needed the character of it which was in the other test that I shouldn't do, but I should have done and that was a lack of communication.

NEW SPEAKER: You don't always know what are the right questions to ask when you come up, it's only when you go home and think about it and then when you come back you don't know.

NEW SPEAKER: The health care professional, say you're given drugs or something like that, if they're not interested, you can tell by a person's body language or facial expressions how much care they have towards a patient. It can go straight in the bin and they don't feel the side effects or anything like that. The patient comes back, "What are the side effects, what's going to happen when I take it?" Unless that explanation comes forward, everybody has a better understanding of it.

NEW SPEAKER: Everyone's always in a hurry and I think that people will shy away from asking questions, because there's that authoritytype role to medical professionals and they're somehow more important and their time seems to be more important than your time. Asking for information you'll better outcomes for patients. Those people, if they understand what's going on, everybody's happy.

VIDEO ENDS

NEW SPEAKER: Okay, that's the video we produced and it's always interesting when you do something like that, where you literally start asking people in the hallway their thoughts, some of the information that comes through. Yes?

NEW SPEAKER: Sorry, I just wondered, is that just internal in the health system, or can other people access that via YouTube or something? It's a great teaching tool and even an awareness for the consumer to be mindful to say, "Hang on a second, it's not only myself or whoever to actually ask a question to slow down and explain something they don't understand."

NEW SPEAKER: If you get my contacts, we can organise for people to get copies if they feel it would be helpful. Was there a particular word that surprised you when you listened to that video?

NEW SPEAKER: Multidisciplinary.

NEW SPEAKER: I loved that!

NEW SPEAKER: I nearly fell over, and I thought in 20 years of working in health care, I've never sat down and explained what the word multidisciplinary means to people. I know I've said things to people like "We'll take that to the multidisciplinary team meeting", now I think, what did they think we were doing? Language and the assumption that people understand our language

NEW SPEAKER: Can you tell us what it means?

NEW SPEAKER: It's a group of different people from different professional backgrounds working together towards someone's care. But yeah, three out of four people we gave that card to talked about discipline. They obviously think we go behind the scenes and start to talk about how to get them to do things.

NEW SPEAKER: Maybe that's needed!

NEW SPEAKER: I thought it was why I was in trouble all the time.

NEW SPEAKER: Human beings are interesting creatures. There are some things that we lack insight in, in terms of our behaviour and how well we do with things. We all think we're good drivers? We all think we're really nice people, even Donald Trump. So Donald Trump has stood at podiums and said "I'm a nice guy", we all think we're nice. When you're a health professional or work in the health system, we all think we're really good at delivering health information to our patients and their family members. So it's a really difficult position we're in when we're trying to help our staff understand issues of health literacy. We're challenging their own notion of how good they are at something, so that gets complicated and they think they're good at it, because that's their aim and intention. They actually want to do a good job. Because they think they want to do a good job, they think that translates into doing a good job with information. But what we mind is that the patient story and the staff story end up being quite different. So we decided to do this video, because when we're thinking about how to help our staff understand this issue more we realised it was the patient experience that was going to be the selling point. It was going to be them telling their story that would help staff to understand what they needed to do differently. It's a shortened video of this in orientation, but we've showing it in a range of contexts with people. We thought what we'd do, though, is try to figure out the impact of the video on staff, so we sent out an evaluation. Whenever you do that, you send out 50 or 100 forms and get 15 or 20 back which is exactly what happened and so we did have a small sample, but they did say it was a useful video and they would consider going to additional training on health literacy after having watched it.

NEW SPEAKER: Sorry, was that to staff?

NEW SPEAKER: That was to staff. These were some of the quotes they put on the feedback form to us, just saying that yes, they recognise that some of the stuff being said was very true and we needed to think about those things. But there was one thing that came clearly out of the evaluation we did on this video. They all thought they did a really good job. It was everyone else, and in particular they blamed the doctors. They saw this as a doctor issue and so that has been really interesting for the members of the team to think about. How do we know target it to make sure everyone understands this is about everyone. We didn't ask specifically about doctors, but we didn't ask about that specifically and we know it's the admin people and the operational staff and everyone in the organisation that contributes to this being such an issue. One of the stories that came through our health service was one of our staff members was out talking to patients on the ward and he said "Oh before you go, can I ask you a question?” She's like "Yeah", he said every time the nurses come to the bedside to do handover they say that I'm selfcared. I'm really sick, I could die, I've got heart problems. He said, "What does that mean? Do they know I'm sick? “I didn't know this before either, selfcare is a nursing term that means that person can get to the bathroom and to the shower and can feed themselves. So he sat for days in this space of anxiety thinking the staff around him didn't really understand how sick he was because he heard the word selfcare and in his head that meant they didn't have to take care of him, he was good. So health literacy is really about stories. Lyn is going to share a couple of other stories with you now.

LYN HINSPETER: As we've seen, health staff think they're communicating well with their patients or clients and that they use basic language, but as you saw in the story that I told earlier, basic language can be misunderstood, people don't always understand that. Also, what health professionals don't always understand is when a person is anxious, they don't always hear very well and it's very easy to misinterpret information. Even simple words or what we think are simple words can be misunderstood. Two... oh, thank you very much. Two more illustrations. A patient was asked by a health care professional to turn round and walk towards a wall so that their gait could be checked. All the person heard was "gait and checked". They turned around to the health professional with a confused look and said "Yes, I understand those introductions, but where's the gate I've got to check?" A simple thing to say would have been "Can you walk over there so I can see how you're walking." On another occasion, a person was asked by a health professional, "How's your diet?” The reply was "I'm not on a diet, I just eat normal food." In this case, the health professional was really asking the person, what do you eat, what's your nutrition like, but having heard the word diet, the client thought that they were expecting them to be on some sort of diet for their health condition and were very confused. Even when we use simple words because of anxiety, because of levels of education, because of a hearing problem, our messages can be misunderstood. When you listen to these sorts of stories, you understand the issues around health literacy and the need to communicate so patients and their families have real knowledge and real information and understand what their health care is about.

JO SHERRING: So one of the things that came out of the video for us is health literacy is about more than words and when you listen to some of the things those people said and they used terms like "a level playing field" and "authoritarian figures" and that was the language they were using, and so we have to remember that health literacy is also about power and making sure that we are actually being equals in the process of how care is delivered. It's about power of our time and power of our training. It's about power of the positions that we hold in health care and it's also about the power of our language. In order to do health literacy well we need to understand there's a power dynamic that exists within health systems that we have to address and obviously with any large culture change that's going to take time. This video isn't about changing the world, it was about planting seeds. Just to help understand that the issue exists and to start questioning ourselves and question whether we're doing things well enough and to be open to training. We see this video as a small part in a long journey and our aim is to do far more with patient stories when it comes to health literacy to help our staff understand. Health literacy forms the foundation for partnership in health care and by extension that means good health care. That's the sort of care we want to receive and deliver as health care staff. That's the end of our discussion. Are there any questions today?

NEW SPEAKER: I'd just like to ask Jo, during the presentation and the research that you're doing with your staff, I haven't seen any commentary about people trying to access the service who come from nonEnglish speaking backgrounds?

JO SHERRING: She was asking there's no commentary about people trying to access the service from nonEnglish speaking backgrounds. That's certainly on our radar to have more discussions around that and we know it's an issue. In fact, we hear stories about people even just struggling with signage in our hospital because of language issues and so that's certainly something that we want to consider as we move forward.

NEW SPEAKER: Any final questions? We'll just take these two and move on.

NEW SPEAKER: Another idea came to me while you were speaking is the use of acronyms in the hospital system. Actually, it's sort of like a gatekeeper system, it functions to keep people out.

JO SHERRING: Even when we have consumers coming to the meetings that's one of the things we always discuss with the chairs of the meeting and have a list of acronyms, because it does divide people. It sets a barrier in place for people's understandings.

NEW SPEAKER: I know carers at various organisations and the issue of jargon especially within hospital committees is quite a challenge, so that's something we need to think about.

LYN HINSPETER: I have a quick story around acronyms. It was a handover. The patient had a significant brain injury. Their mum was sitting with them during handover and the nurse said "Oh, her GCS is 15", now the mum freaked. Now on a glaucoma scale, 15 is the best you can get, but mum just freaked.

NEW SPEAKER: Just taking up about nonEnglish speaking, there's another side of that as well and that's cultural norms within those groups. So like you'll find some of the Middle Eastern and even some Aboriginal group clans where if it's a care issue they'll only listen to either a male or a female, if the introduction comes from the other sex and they're not willing to take it into account.

NEW SPEAKER: Community and law is what you're referring to. And another sort of problem is we really don't have a good communication system between the hospital and the normal community health provider. The number of people I've seen bounce back to hospital because the hospitals change their medication. They go back to their GP. The GP writes them out scripts for the old medication. They take those, there's a contradiction. Bang, back into hospital. I've even seen people die.

JO SHERRING: Those issues highlight the importance of the consumer partnership work we do, to have people in the spaces with those staff members saying those things and to have people prepared to be videoed and telling their stories, because that's the stuff that actually changes staff's minds about things. They tend to think that people are fine. If people aren't complaining things are fine and we know that's not the case. The very essence of having consumers embedded in the health service I think begins to address that and make sure at every level we're asking those questions.

NEW SPEAKER: I think there were a couple of people who denies understand or didn't hear Kevin's comments and his comments were an attempt to pick up on a point about people from nonEnglish speaking backgrounds or people from culturally and diverse linguistically backgrounds. It's not just the language, it's questions of culture and who speaks on what issue, who will be heard when they speak on both issue and both those things need to be taken into consideration. So I'm going to have to call it to an end now. For those of you who have more questions, I'm quite sure our wonderful speakers will talk with you over lunch. Thank you for listening. Can you join me in thanking the speakers for their presentation. (APPLAUSE).

I think what we'll do in the next session is when we come to asking questions, I will repeat the question before we have an answer and hopefully that way everyone will understand. If these guys would like to take their seat, thank you, it was a fascinating presentation. I would like to ask to the stage, I've got Christopher Howard and is it Tiko... I can't pronounce your name. This is one of the important things about working with multicultural communities. Just Tiko is fine, please forgive my incapacity to pronounce your name. The next presentation there are a couple of people just leaving the room now is entitled life and peer navigation for people newly diagnosed with HIV. Chris has worked in Queensland HIV, the centre itself for over 20 years. He's lived with HIV for over 30 years. He is the life and program manager for Queensland Positive People. For those leaving right now, can you avoid conversation until you leave the room. That will make it easier for everyone to hear, and Tiko is a peer navigation team leader in Brisbane, studying for a Masters degree in health management at

Queensland University of Technology. Prior to that, he finished a medical degree in Indonesia. Please welcome both Chris and Tiko to the stage.

CHRISTOPHER HOWARD: Thank you for the kind introduction. I want to acknowledge the traditional owners of the land on which we meet and pay my respects to elders past, present and emerging. I'd like to acknowledge our key funders for the peer navigation program. Queensland Health has been a significant health care, the HIV Foundation, the University of Queensland school of population health and our sister organisation in Canada, in British Columbia Positive Living, British Columbia.

NEW SPEAKER: We just want to let people know there's a hiccup with the next session next door which was to be "somebody Maelstrom". We're going to ask this session to hold for a minute or two while we get organised.

CHRISTOPHER BROWN: I'd like to play some holding music, but I'll refrain.

JULIE CONNOLLY: We're all here for a few minutes, maybe we could take the opportunity. I'm going to hand this around randomly and ask you guys to introduce yourself and tell us a bit about yourself. It would be fascinating to know who's in the audience as well as who's speaking. Would you like to start? Someone over there.

NEW SPEAKER: I'm Maureen. I became a carer representative working with the NDIS in Brisbane on a working committee for the ABI centre that my brother was a resident in and now as a result of that work, I'm on the NDIS Council as a care.

JULIE CONNOLLY: Can we all welcome Maureen.

NEW SPEAKER: I'm Jill from Brisbane city, I'm a consumer. I have a hearing loss and I've been struggling this morning to maintain that communication. Can I ask for people to speak clearly and not too quickly. It changes my life.

JULIE CONNOLLY: We'll do our best to do that and I will hand over for Peter in one minute, but can we welcome Jill. She's come to be with us today and is brave for telling us what she needs. You should be congratulated for that, thank you.

NEW SPEAKER: My name is Peter, and I'm profoundly deaf. To emphasise what Jill has said, with the advent of technological change, we have noticed that people tend to speak much more quickly than they used to. It's difficult for people to keep up, not just for people with hearing loss, but many people, particularly older people 'cause it takes some time for people to actually process information and they don't have time if people speak too quickly, which of course includes health professionals, because they always seem to be in a hurry.

JULIE CONNOLLY: All right, can we welcome Peter. People are clapping. I sometimes teach at the University of Queensland and every time students at student evaluation say "Can you just slow down?" Colin, would you like to introduce yourself to everyone?

NEW SPEAKER: Colin Sedgwick, I'm a local government rep, I'm from Yarawa about half an hour east of here.

JULIE CONNOLLY: That's great, thank you, Colin. Colin has travelled from east of Cairns to be here today, so we're very pleased. Welcome, Colin. It's better than sitting around and staring at each other. It's amazing that we've had the first people that we've asked to introduce themselves have come from a long way away to be with us today and they've overcome barriers and they're asking us to help them to do that. Am I speaking too quickly? I'm doing it again! Would you like to introduce yourself?

NEW SPEAKER: I'm Ben, the director of remote facilities for NorthWest Hospital and health service and I'm based in Mount Isa, part of my cohort, I look after two discrete communities which is Mornington Island and Doomadgee.

JULIE CONNOLLY: That sounds like quite a challenge, great to see you. Who would like to go next? Jennifer?

NEW SPEAKER: I'm from Cairns also, I work with Allied Health in Cairns Mental Health Unit. I work mainly with those who hear voices. Unfortunately, there's no university qualification that I can go to seek help with that work, so I'm studying at the moment with Swinburne Psychological Science, which I may be ending up with Queensland University. It's too far away. I have just one question, there's a lot of people who are directing service delivery to clinicians and people like myself who are on the frontline. How about we talk about what the Indigenous people talk about? How about we start with community?

NEW SPEAKER: Thank you very much for that comment, Jennifer. Can we get started? Okay. Thank you for everyone who took the time to introduce themselves, I really hope that across the course of today that you can meet new people, one of the ways of starting with community I think is talking to community and getting to know the people who are in the room. I'll hand back to Chris. Thank you very much for your patience.

CHRISTOPHER HOWARD: A little bit about our organisation. The historical role of peers in the HIV response, so for those of you who don't know what HIV is, it's the human immune deficiency virus that causes AIDS, or AIDS acquired deficiency syndrome. We're going to talk about the contemporary role of peers in the response, the peer navigation model that we developed. We'll hear from Tiko in particular around his perspectives as a peer navigator and we'll look at peer navigation from now and beyond. A little bit about us as an organisation, so we were founded in 1989, essentially to support people living with HIV across the State of Queensland. Our vision as an organisation is to help improve the health and wellbeing of those people living with HIV across Queensland and encourage individuals to be informed and empowered and to lead lives free from stigma and discrimination. Our mission as an organisation is to provide a comprehensive range of services that meet the health and wellbeing needs of individuals living with HIV and ensuring these are delivered in accordance with internationally recognised best practice and peer navigation model which I'll talk about, is actually one of those. I mentioned that the model was made possible through a number of different funding sources and is adapted from an internationally recognised best practice model that is provided in Canada. I just want to talk a little bit around the historical context of the role of peers in the HIVAIDS response, so for some of you in the room who might remember in the early '80s the emergence of AIDS in particular, it required a very significant involvement from the community, the people living with HIV and those that were dying from the virus were actually the carers, they were the educators, they were the advocates, they were the activists providing social, emotional or practical support to their friends, their colleagues, their loved ones and it was done primarily from a position of volunteerism. Those individuals were really not paid for that work, there was a lot of stigma, a lot of fear, a lot of ignorance around HIV and AIDS. It required a community driven response. I don't know if you know the Ottawa charter that was developed in 1986? Following on from that was a principle that was endorsed globally, which referred to the greater involvement of people living with HIV and essentially, this evolved over time to not only greater involvement, but really a meaningful involvement of people living with HIV. Essentially utilising their lived experiences, their personal experiences to inform the broader HIV response, and that was founded on some key principles about local responses to HIV, that policies and programs were tailored and responsive and there was a focus on self-determination and personal empowerment. This is a diagrammatic... I'm sorry it's a very busy view, but it's actually the GIPA model. The key principles are the branches of the tree and the leaves form the actions, the recommended actions. So if anyone wants the link to that to have a look at it closer in depth I'd encourage you to come and see me. But it's a really fascinating model to implement in practice.

NEW SPEAKER: Could you just tell us what GIPA stands for?

CHRISTOPHER HOWARD: It stands for the greater involvement of people living with HIV and AIDS and MIPA stands for meaningful involvement of people living with AIDS. I just wanted to turn our attention towards looking at how HIV has changed over the years. So in 1983, the HIV virus was identified by a number of clinicians and then basically until 1996, there wasn't any effective treatment for the management of HIV and a lot of people unfortunately succumbed to the virus and died. But in 1996, there was some ground breaking clinical evidence as a result of extensive trials that demonstrated that triple combination therapy, so that's the utilisation of a number of different therapies was very effective in suppressing the replication of virus in the body. What we did see was the number of people that were living with HIV started to increase and the number of people dying from HIV declined. Then very rapidly over the past few years we've seen significant advances in treatment and there was some major milestones and I won't go through them, but they're essentially here on the slide. Really, the take home message from this slide is that there was resounding evidence that early intervention or early treatment following a diagnosis of HIV not only prevented disease progression in an individual, but also prevented on ward progression sorry, on ward transition of HIV. So there were two key elements which it's now known as TASP, or treatment as prevention. That's the prevention of disease progression of a person living with HIV and the prevention of onward transmission. In 2013, the United Nations AIDS Committee part of the World Health Organisation on the basis of treatment as prevention developed some modelling to basically say by 2020 if they had 90 per cent of people that actually knew they had HIV, that was their target and that 90 per cent of those people that knew they had HIV that were actually treated and then 90 per cent of those people that were treated for their HIV had undetectable virus. That is, that the medication suppressed the virus so it was not infectious, that they could virtually see the elimination of HIV by 2020. What that essentially informed was some strategic focuses. There was the global United Nations' AIDS targets of 90, 90, 90 and then there were strategic objectives embedded in Australia as 7th National HIV Strategy, which is currently being reviewed for 2018 and also, the Queensland HIV action plan. So these principles became embedded as strategic objectives in all these levels of planning. As an organisation committed to the health and wellbeing of people living with HIV, we identified there were a number of ways we could respond to support those strategic targets, but also support the health and wellbeing of the PLHIV population, so we developed two distinctive programmes, one of which is a peer testing clinic. This is where peers in our community test those most at risk of HIV for HIV and other STIs and we have a clinic in Brisbane and one on the Gold Coast and we also developed the Life + program which was about addressing the other 90 per cent. 90 per cent of people living with HIV would be on treatment and 90 per cent of those people would have undetectable viral load. I'm very happy to say that the model that we submitted to the department in 2015 which was looking at an integrated suite of programs was actually funded and that the department for the first time recognised that a PLHIV peerbased organisation was best placed to respond to the holistic needs of people living with HIV across Queensland. So some of the other services that we provide in addition to peer navigation is complex case management for individuals living with HIV, health education information and resources and stigma and discrimination.

So the broader goals of the program are actually listed on this slide, but I think most of the goals are achievable through the peer navigation program and a particular focus for us is preventing HIV disease progression in PLHIV and improving the overall quality of life of our peers. I talked a little bit earlier around how peers have always been central to the HIV response and primarily in the role of volunteerism. This slide here just models where peers now fit within the broader response to HIV. So we work in the peer navigation program alongside health professionals to help people newly diagnosed with HIV to synthesise that diagnosis into their lives by the provision of an early intervention model for individuals following a diagnosis. As is the process for any program development, there's a very logical sequential flow, but I really wanted just to highlight that individuals living with HIV were at every step along the way of this process and engaged in the focus testing and the development, in the delivery. So PLHIV were involved at every point. I'm now going to hand over to Tiko to talk a little bit about the model and the lived experience.

SATRIO NINDO ISTIKO: Thank you, Chris. If you look at this picture, the white person in the middle is newly diagnosed and you can imagine how complex and overwhelming it is once you are diagnosed with HIV to navigate the HIV care and treatment. What we did is we did a needs analysis result to identify the information and support needed for that person and the result of that analysis are basically one, about information, people need not only information about diagnosis, treatment and navigating HIV care, but they also want information about disclosure, about legal rights and responsibility and other topics. In regards to support, they want someone who can provide emotional and social support and can help to put their diagnosis into perspective and help to ease their fear and anxiety of becoming an HIV positive person. What's really interesting is that apparently they want this information and support to come from a trained PLHIV peer worker and they want to meet this peer worker in a face to face setting and they want it right from the get go, since day one of diagnosis. So what we did is created this model in which client is at the centre of our model and then we have three integral parts starting from the peer support, in which in this part the peer navigator will use their lived experience as an HIV positive person to provide that emotional and social support and in the navigating health system part, the peer navigator will help them to build trust with the doctors how to access treatment through the pharmacies and how to understand their lab results and through the peer navigation, the peer navigator will deliver education by using educational modules. These education modules basically are categorised into two categories. The first is the core modules and the second is elective modules. For all clients they have to go through the core modules, in which they will talk about HIV one on one. They understand the virus and then the treatment and they're navigating the health system, but when it comes to the elective modules they get to select which topic they want to discuss and that's because in delivering this educational modules it is based on the adult learning theory. Now the intervention itself is very highly structured. It's 15 hours for a client and that can range from 4 to 8 weeks and it's very flexible in terms of setting. The peer navigator can go to the doctor's appointment with the client or meet at a coffee shop and what's important is towards the end of the engagement the peer navigator will assess whether the client is actually confident to manage that diagnosis and whether there are other issues that need to be referred to a case manager. Now because we need to provide a very good quality, safe and culturally appropriate services, we have peer navigators all across Queensland. Mostly they are in Brisbane, but we also have in other regions, as well. We have females, we have heterosexuals, there are peer navigators from Africa, Aboriginal and Asian backgrounds and they also have other lived experience from mental health issues, alcohol and drugs and also homelessness, so that we can address that intersectionality issues within the clients. When we provide training and then we provide the skills development and also ongoing supervision to make sure that the service that we provide is safe and is of good quality. So for me, how do I work within this model? For me, being a peer navigator is about empowerment. I empower the clients and I empower myself, so I have to bore you poor people about a little story about myself, in which I came to Australia last year as an international student to study Master degree in health management and I was diagnosed just one month after I got into Australia and then I have to navigate the Australian HIV care which is so simple to understand and that's an understatement! Of course, unfortunately there's people that helped me to understand that and how to better manage my diagnosis and in June, I applied for the job to become a peer navigator to work with people who don't have access to Medicare. Now what we have to understand is prior to that, I'm just a consumer, I'm a consumer with a very complex issue just like any other consumer, but starting as a peer navigator, this consumer can provide services to other consumer, and after working a while, I discover even more complex issue with my home country in which there's a persecution towards the Indonesia LGBTIs and I apply to become a refugee here in Australia and so since December, I'm basically an asylum seeker, but thankfully with my job as a peer navigator and my study I keep on going and I find myself now as a team leader of this peer navigation team and right now, I'm presenting in front of you all, not only as a peer navigator team leader, but also as a gay HIV positive asylum seeker.

APPLAUSE

Thank you. I months ago about people who don't have access to Medicare, in which apparently there's another term, Medicare ineligible, because obviously we need more terms. Medicare ineligible is people who basically have a working visa, student visa, working holiday visa or holiday visa, they can't access the Medicare and therefore, they cannot access the HIV treatment and the HIV treatment itself, it will cost about $1,000 to $1,500 a month. That's the first regimen that the doctors prescribe, so we have to find other ways for these people to access treatment. If you look at the building blocks on the top, that's the story that we want all people living with HIV to go through. They got diagnosed, they are linked to the care, and they retain their linkage to the care. They're committed to the treatment and then they achieve that final suppression or undetectable viral load in which their blood the volume of the virus is really low. But for Medicare ineligible, they have access to navigate that various access to treatment. It's really difficult, it's not straightforward and then there's a financial barriers that I mentioned and then there's a low health literacy, because it's not easy to understand a health care system in a foreign country and also, they have to navigate complex migration system, because a lot of them wants to become permanent resident, but to become permanent resident if you're HIV positive you fail the health requirements and you have to waive the health requirements. Very complex. Basically, up until now I've supported 10 Medicare ineligible clients out of 76 peer navigation clients and most of them are males, most of them come from Asian countries and most of them hold student visa, but what I consider as a big achievement for the peer navigation program is that all of them started training within 3 months and that's the goal of our programs and we're very proud of that, because we've been working hard to achieve this and we get amazing feedback like people saying they're really confident now in managing their HIV. That rarely happens, it's like we're giving a fast track process to people to achieve that level. And so I guess the benefits of being a peer navigator for me, it's all about empowerment, like I said. I as an asylum seeker get to develop my skill, apply what I studied about quality improvement, people management, program evaluations and this is the skills that Australia needs and I get to contribute to the Australian society in general and PLHIV specific and I'm proud of that. So to discuss more about the outcomes and challenges, please welcome Chris. (APPLAUSE).

CHRISTOPHER HOWARD: Thank you Tiko and thank you very much for sharing your very personal story. Just going to touch quickly, since the peer navigation program has been up and running, as Tiko indicated we've had 76 clients, 10 of which have been female and the balance male. Interestingly, the demographic there for the age range aligns with, of course, the epidemiological data from Queensland Health. It's a very concerning fact for us as a PLHIV organisation that we continue to see the rate of diagnosis amongst Aboriginal and Torres Strait Islanders increase and that's represented in this slide that ten of the people that we've supported since the peer navigation program has developed have been Aboriginal and Torres Strait Islanders. We just want to talk a little bit

NEW SPEAKER: Can I just check noone is getting dripped on?

CHRISTOPHER HOWARD: I want to talk a little bit around the challenges. I didn't necessarily want to paint the implementation and operation of this program as being plain sailing. We've certainly had our challenges in employing peers to work in the role. Some of those challenges have been peer navigators working within their scope of practice and stepping outside of that doing, as you can appreciate, peers work in this role for altruistic reasons and they're really wanting to help their peers. They sometimes go a little bit far, so some boundary violations have occurred. We have had peer navigators through lived experience that bring great strength to their role that have a prior history of drug and alcohol misuse. We have seen some peer navigators triggered and relapsed. So the need for intensive support, ongoing supervision and the retention in alcohol and other drug programs or mental health programs are really critical to ensure the health and wellbeing of our peer navigators. Supervision and support is challenging for your geographically dispersed team of peer navigators right across this State and... I did correct this misspelling, but it's actually casual employees, but casual employs, each engagement with a peer navigator is 3 hours, so we pay them at a casual rate, but under the award it actually can be quite expensive, so that's an ongoing challenge. Technology use, also. All our peer navigators are armed with mobile phones and mobile tablets and for some peer navigators it's been a real challenge in terms of utilising that technology and also data entry. We capture quite a lot of data. We're partnered with the University of Queensland for an evaluation of this project so that does require the inputting of data, as well as our reporting to Queensland Health. Basically, future plans for peer navigation, so we're extending the program to those at risk of falling out of care. So what our care managers identify as some of the clients they're working with are at high risk of falling out or disengaging in care and they identify as significant value that a peer navigator can provide for a time limited period, so we're extending the program to that. Strengthening the capacity of all peer navigators to work with Medicare ineligible PLHIVs, so Tiko will be developing module training for all peer navigators given that Medicare ineligible peer navigators, Medicare ineligible PLHIV are across the State, and the thing that's probably stood out for me in the development of this program is that one size doesn't fit all. I think in recognition of that is tailoring and adapting the program more specifically to meet the needs of Aboriginal and Torres Strait Islander people. We talked about this as being an early and brief intervention model. That just doesn't work for some Aboriginal and Torres Strait Islander identifying people, so we acknowledge that we really need to work with the community to adapt the model in a more suitable way. What I can sort of say and it's not on this slide, is that we have been successful in securing funding for Townsville to implement a further innovation which is a HIV, STI peer tester as well as peer navigator position which will sit within the health service within the Townsville region, so it's a pilot project. It has been funded, but yet to be implemented. Take home message is really from here, is that peers have always been central to the HIVAIDS response, as I said earlier today and we have a vital role to play to support the global achievement of those targets. We as individuals within the community, we're here to empower and support our peers and peer navigation really does that in a really proactive and constructive way and the model continues to adapt to the changing needs of our consumers essentially and to our other key stakeholders. Basically, questions, if we have time.

NEW SPEAKER: We most certainly have time. Tiko, would you like to join Chris. Does anyone have a question, I'll bring the microphone to you? Steve down the back.

NEW SPEAKER: Chris and Tiko, thank you for a very educational presentation and obviously the innovation to establish a peer network needs to be congratulated and continued. I actually am HIVpositive and have been since 1983 and during the 80s and 90s we undertook a major public education program and worked across multiple sectors then and there was a degree of success, although the program didn't actually focus on Aboriginal and Torres Strait Islanders and was lacking in that respect. I'm wondering, is there room today for a more prolific or higher profile public education program? Because we are seeing certainly in North Queensland some rise particularly in STIs and certainly HIV Indigenous communities. I'm wondering what, if any strategies, you or others might be planning to raise the bar in terms of public education?

CHRISTOPHER HOWARD: Thanks, Steve. So the question was really what are we doing as an organisation to raise the profile of HIV, particularly in Aboriginal and Torres Strait Islander communities. Would that be a fair?

NEW SPEAKER: STIs?

CHRISTOPHER HOWARD: Our role primarily as an NGO is really to work with people already living with HIV. In terms of the prevention space, the government has funded other organisations to work in that area and in particular with the amount of money the minister's committed to the Aboriginal and Torres Strait Islander health strategy for the north, $15 billion, it's really hopeful that there's something very constructive that comes out of that. We're very keen to partner where we can. We have an Aboriginal and Torres Strait Islander peer navigator in Cairns that currently provides outreach support to Townsville and as I said, we're very keen to continue to develop and adapt the model to ensure that it's more appropriately meets the needs. I think the thing that as an early intervention model, the idea of peer navigation is to help people synthesise the diagnosis into their lives and prevent the risks of falling out of care and we do know that Aboriginal and Torres Strait Islanders are at greater risk of falling out of care. That's why this program, but we understand there are real complexities in engaging in the community and needing to be sensitive to the individual needs.

NEW SPEAKER: Do we have any other questions? We've got one, two and three. Just to let you know, the lovely Helen checked and unfortunately there's nothing we can do about the dripping sound, so apologies if that's distracting.

NEW SPEAKER: Thanks for the presentation, it was wonderful. I'm interested in the peer navigator model as it's adapted to other kinds of diseases and conditions and the one thing that I'd like to ask, I've got a lot of questions, but the one thing I'll ask about is what do you do about the boundary breaches, where the peer navigator and perhaps they've gone outside the scope of their practice. How is that handled and what have been your main issues with that?

CHRISTOPHER HOWARD: So the question was peer navigation adapted to other health care. There are two questions. One relates to peer navigation within other health care settings.

NEW SPEAKER: Mainly the second part, boundary violations.

CHRISTOPHER HOWARD: They're lots of fun! I'll pass back to Tiko.

SATRIO NINDO ISTIKO: I just repeat the question. The question is how do we handle whether there's a breach of boundary from the peer navigators themselves? There are a couple of layers, just like any other quality improvement strategy, you cannot depend on just one method, so one is that we provide formal supervision every two months, so that's to talk about a lot of things, including engagement with clients and then there's an informal feedback that I always give to the peer navigators every time I see a warning sign. That can be from the report that they just wrote and if I sense there's a gut feeling that it's just not right, I always tell me peer navigators that I'm going to be open and honest about it and then we're going to have a discussion about it. Then also, I always encourage the peer navigators to plan and then seek approval and then act. So if they're kind of thinking about a strategy that they want to utilise to engage with the client and they're not sure, how they may be overtly confident about it, have a check with me first. Talk to me and see what plan do you have and then we discuss that, so that's how I mitigate the boundaries. But when it already happen, you don't punish, you don't use punishment as a centre of the philosophy of managing breach of boundaries. But instead, it's about open and honest discussion with client as the centre. So we have to get a clear information about what happened to the client and then we need to be clear about what exactly, how the peer navigator responds to that and then we created a plan of action from that information.

CHRISTOPHER HOWARD: Thanks, Tiko. I might just add that where people have relapsed back into drug and alcohol use, basically we support those individuals to engage in a treatment program. They step aside from their role until such time as they're stabilised and we're also cautious about how we link those people, so we don't link those peer navigators necessarily to people that may trigger some of those behaviours. It's a really important and our board as you can appreciate, wanting to ensure that risk is managed. Some of those other challenges where we have peer navigators in rural and regional communities are that socialise and sexualise in those environments through social media and other mechanisms, so we provide very clear guidance and support around that. As always with any other ethical or boundary issue, we always encourage them to seek guidance and support be open. In terms of adapting peer navigation to other health care settings, look I believe it's done quite widely within the mental health sector and in HIV it is done in the UK, in Canada and in San Francisco, I believe.

NEW SPEAKER: Thank you, Chris. We are fast running out of time. Two people have indicated they have a question, ask them to ask their questions and if you can respond briefly to both of them, that would be great.

NEW SPEAKER: I guess I was interested in the opportunity especially for your volunteers, your peer navigators to transition over into doing that support work in other areas?

NEW SPEAKER: We've got one more up the front.

CHRISTOPHER HOWARD: Certainly the board are very keen to explore the expansion, for example, peer navigation for injecting drug users for example. It may be for sex workers, for other marginalised and at-risk groups to help support those individuals to engage in care.

NEW SPEAKER: I was just wondering if you had incorporated within your peer navigation models those that are suffering from hearing voices, which is associated with paranoia and claiming the HIV as an external factor coming from such thing as the devil instead of understanding it's a human acquired causal? What are you incorporating within your peer navigation models towards assisting these people, because I don't see them in mental health units at the moment?

CHRISTOPHER HOWARD: That's a very complex question, but essentially we really work with an individual around exactly where they're at as an individual. For example, we've talked very specifically about a very protreatment approach, but as an organisation of people living with HIV, we respect an individual's choice to choose whether they engage in treatment or not and similarly, that relates to how they perceive the acquisition of HIV and so forth. Where we identify there may be other ongoing issues for that individual, it may sit outside this scope of practice of the peer navigator, so we'd be keen to explore how we might work with that individual about providing other supports through case management program. We want to ensure that what we're providing, peer navigators are safe in the work they're doing and we respect the duty of care to ensure we're providing the best support to PLHIV.

NEW SPEAKER: Thank you. Can we thank Chris and Tiko for their presentation and also for their courage in sharing their own lives and experience. Thank you.

Okay, so we have our final presentation for this morning's session. Thank you to all of those who've just arrived. I don't know if anyone is planning to go elsewhere. I'll give us a moment to make sure we're all seated. This next presentation is by the Queenslanders with Disability Network, as I understand it, the Townsville local support group coconvenors and unfortunately, we weren't able to organise the stage so they can join us up here, they'll be joining us at the front. We have Michelle Moss, Daniel Flynn and Peter Gurr. Michelle, if you'd like to come up, has worked in human services for the past 25 years. She has worked across disability, health and domestic violence. Done direct support work and counselling, behaviour support, consumer and community engagement, so that's quite a CV Peter Gurr holds several volunteer positions for the Queenslanders with Disability Network, including at the Townsville coconvenor, the board director, an NDIS participant readiness peer facilitator. That is quite a lot of work, Peter. Congratulations. Finally, Daniel is the coconvenor of the Townsville local support group which is by and for people with a disability. Daniel I've got a little bit of information about your condition, but perhaps you'd like to share that yourself when you get the chance. Daniel has extensive experience with the disability sector, he's been the facilitator of many local support groups. Please join me in welcoming our next presenters to the front.

NEW SPEAKER: While we're getting the other bits of technology working, I will get started to introduce ourselves and what we're going to talk about today. We're all part of an organisation called Queenslanders with Disability Network. I'll hand over to Peter, who's going to talk about what QDN does and what we do.

PETER GURR: I'm Peter Gurr, a Townsville local and used to be a business owner here in Townsville. I'm also an MS person, diagnosed six years ago, so I had to close my business down and take it a little bit easier to try and get myself right, which is not going to happen unless some health people come up with a miracle. QDN, or Queenslanders with Disability Network, they are for people by people and run by everybody in QDN has got a disability, or a family or partner, member with a disability, so we're all in it together and we all know what each other's... not disability, but that we're all on the same level of communication and everything about our problems and everything else. Statewide, we have 1500 members now. When I first started at QDN we only had 800. So we've grown, nearly doubled and it's our 15th year anniversary this year, so it's a bit of a bit year and a bit of a milestone. We've got 12 staff, but that could be changed by today, who knows? They change staff pretty regularly, because we've got casual staff and they move on and we get another casual staff person in to help us out with all sorts of stuff that we do. The seven people as I said on the board and basically we're now around the State, plus a few in Brisbane. We're spread far and wide in the State. Our motto is, nothing about us, without us and we work with each other and we try to change policy within government the way they look at people with disability and how we go about that is up to Michelle, because she's at that system change, that's why we pay her the big bucks, I guess.

MICHELLE MOSS: Just to give an overview of the work of QDN, we are funded as an information referral service and we're funded to undertake systematic policy to be the voice of people with disability and that's across a range of policy areas depending on what our members and our local support groups tell us about what's important to them. We also are funded at the moment to undertake quite a bit of work in the space of National Disability Insurance Scheme, the NDIS. I think an important part of the work of QDN is it lives to the motto of nothing about us, without us and it's very much about a codesign working, that it's informed by people with lived experience. I guess we wanted to talk to you about the work of the disability support organisations, which is where the local support groups fit and to set the scene in terms of disability we're in the biggest moment of transformational change in the disability sector. We've got the rollout and implementation of the National Disability Insurance Scheme, which I think is a great example and really shows the power and the passion of people and what can happen when people come together about something that's important to them and to bring about that change. For the first time ever in the history of the disability sector, we saw people with disability, families and carers and service providers unite around a common vision that we needed to do things differently to deliver support and services to people with disability and I think you would have all seen the evolution of the NDIS in that space. The NDIS gives people with disability choice and control and it's a different way of operating and a different way of doing business, so in the wisdom of the National Disability Insurance Agency, they thought it's really important they start to build the capacity of people with disability and their families and carers to be ready for how that new scheme's going to work and to be able to navigate as we've heard, a very complex system and to be in a place of being empowered to do so. So the initiative that they funded is the disability support organisation and that was to establish networks of people with disability, or networks of families and carers to be able to connect each other and provide that support, information and an opportunity to work out how they were going to prepare for the NDIS. Queensland, we only got funding for one DSO, so that was Queenslanders with Disability Network, there's another 18 across the country, most of which are in Victoria and NSW. Just briefly in terms of QDN's role as a DSO, we've had the job to establish 25 local support groups across the State. They're in various locations. We're going to talk to you today about Townsville, but we also have a local support group in gnaw Manton, we have one in Charters Towers about to establish in Cairns and then ranging across mainly the east part of the coast and South East Queensland. We had a request from our group members that there was to be some groups specifically for people with intellectual disability, they're led by people with intellectual disability for people with intellectual disability and we've got a couple of virtual networks. There's some information up there about the work that we do to provide support, training and the things that all of our volunteers and support group need to undertake the very complex job of bringing together groups of people and sharing information and supporting each other. Peter, I'm going to hand over to you to talk about what a local support group is and what they do and how Townsville got started.

PETER GURR: A local support group is like all local support groups that get started. They're usually about somebody that wants information or a group of people that wants information. In this case, it was people with disabilities coming together wanting information about the NDIS and how they were going to navigate that system. Now, everywhere we went, there was not enough information given on how we were actually going to do that. Some seminars we went to were very good and we were able to find that information quite easily. Other organisations or seminars that we went to sort of counteracted that information that we just got from the last seminar. So it was very confusing for people with disabilities, so we had a product that was given to us by the government and by the NDIS straight from them, so we were able to sit there and think about how we were going to develop this and do it. So what we did here in Townsville was we sort of followed the same lines as what had happened in other cities and Brisbane and elsewhere in Queensland where it was already running. So we run them guidelines, but not every had fits every head so we had to adapt it for the Townsville area even though the disabilities never changed. CP L doesn't change from here to Brisbane and everything else, nor does MS, nor does other things, but the people changed and their wants were different. It was rolling out in Townsville first, so the wants were information and we want it right this very minute, because we're going to roll out and what we did was I went to my individual groups and we had only four people that wanted to be in the local support group and we thought, is this worth it? Then, okay, we will do it, we'll just try it. So we got together, all of the city's leaders from around the area and we said "We're going to have a meeting, QDN's going to come up here and have a meeting", and QDN came up, the staff and myself as a board director, and we sat down in a room at the local PYC and we talked to the city's leaders and straight after that meeting, we told them what we were all about and when I say "the city's leaders", it was the city's mayor, the city's councillors and other people that were right up the very top echelons of Townsville, plus the service providers, and we needed them to be in the room so we could get their support, as well. Because they were the ones that had the participants that were going to be going into the NDIS and staying with them, and all we wanted to do was give them the information.

We weren't trying to steal them, we just wanted to give them the information that they needed to be able to go on in a peer-led setting and it's amazing how well it worked. We only had I think in that first meeting, eight people and four of them I think were made up of staff from QDN, so there were only the four people that turned up. The next meeting, I think we still had eight, but there was four new ones with disabilities, and the second meeting, the third meeting we slowly grew. I started going away a lot to Brisbane to do other work with the board and with QDN that I decided that I was going to make a precedent here in Townsville and I talked to QDN and said "We need to have coconvenors in all of these groups and we need to bring other people along and nurture them along and give them a go at taking a more senior role in the groups in a like "you do it one month and then Johnny, you do it the next month" and have that turnover of people so they all got a go, and they all got a chance to be heard and also, to give their information that they thought was crucial to them that might be crucial to somebody else. I got a convenor which was Daniel, I brought him online and it has worked out very well since that day and we've been going a bit over a year and a half or something. So we started at a really good time, where we had 12 months before we were rolling in and it was into the NDIS, we were able to share a lot of information that people needed and wanted and we were able to go back to the NDIS and the leaders like QDN, to get the information from government on the needs and wants that we had in our local community and our group grew to 25 in no time, because of that and that it grew further from there. I'll hand it back to Michelle, and she can ask the next question of us both, I guess.

MICHELLE MOSS: And I think what Peter's been talking about is that we know for all groups there needs to be a purpose for people to come together and the NDIS was certainly that driving change for people with a need and desire to want to get the best out of the NDIS that they could. So Daniel, you went about that in a particular way of meetings and how you met and what you focussed on. Do you want to tell people about that?

DANIEL FLYNN: Sure, thanks, Michelle. So I came into the local support group fairly early in the piece and I think within 6 months or so of joining, Peter asked me to share the load and I at that stage had spent some decades working in the disability sector in various different roles with facilitating support groups, advocacy, working with different levels of government and so forth. We looked at basically... I think when I came on board we had about seven or eight months before we were expecting to roll out for the NDIS here in Townsville and it was expected that the lion's share of the people in the room would transition fairly soon thereafter. So we broke down the task of how do we get ready, and what do we need to know so that we get the most out of the scheme the first time around? Because we had heard many, many times from many, many sources that it's really quite important to get this right the first time, because after all, it is your life and if you have to wait another 12 months, then that's 12 months where things may not be as good as they could be. So we spent six or so months with Peter, mostly in Brisbane at times due to his other duties, going through lots of planning around what does it take to have a good life and what does it take to actually be included and be a welcome and participating part of your local community? I think in terms... actually, I might leave it there and come back to that in a moment.

MICHELLE MOSS: I think that's a nice segue too, because the group has been about supporting people at an individual level, but it's also been a great change agent at a community level and at a systems level and I think that's something else we wanted to share of that impact that the power of people coming together can support at the individual level, but it also can have impact on changing community. We know that the NDIS is just an enabler in people's lives and that the real issues that members talk to us about are how to get affordable and accessible housing, how do I get good health care that meets the needs of me as an individual? How do I access the community through transport that supports me? So these are all the things that people across the groups across Queensland were talking about, it's the interface issues with those mainstream services, and how do we drive that change to get better outcomes for people? So Peter, do you want to talk about some of the community level work we've done?

PETER GURR: At a community level here in Townsville, I'm also part of through my work at QDN I got offered a position with QCOSS as an emerging voices speaker at different events and QDN and QCOSS got together and got to talking to the Townsville

City Council and a few other leading organisations here in Townsville in government, and we got the NDIS involved and we just had one yesterday and the day before. It was the annual QCOSS, QDN, NDIS changing lives, changing community conference. Now we had 12 months ago and I'm one of the organisers on both and it was such a success the first time round that we decided that we'd do it again, so that's something that we did just as a trial thing 12 months ago that brought the entire community of people with disabilities and carers, community leaders, everybody together all to work as one for two days, and some of the information and some of the work that we've seen yesterday and the day before around systems change in government and change of thinking through people with disabilities and without was nothing but amazing from a person that is a tradesman, a building contractor, still licensed in Queensland and a business owner and now a person with a disability I am just sheer amazed at some of the things that I've seen in the last two days and I've seen over the period of time with the DSO and different things that we've done here in Townsville. But we've also, Daniel and I, done a lot of conferences and other things that QDN has opened up to us, including this, what we're doing today has only been available to us because of our association with QDN and the work that we do with those guys and their knowledge and their commitment to us and to the community. So it's very important that all people with disabilities can access you by accessing us and getting your knowledge by being able to be here with us, and I'm privileged to be here.

NEW SPEAKER: Michelle, we have 10 more minutes, so if we can wrap it up, we can have questions.

MICHELLE MOSS: I'm going to hand it over to Daniel to do I guess a bit of final information at that systems level, the role of the groups has been at that grassroots, what is happening on the ground and that has informed lots of really big picture policy change and I'd just ask Daniel to share a story about transport.

DANIEL FLYNN: I'd like to say that one of the wonderful things that we have seen is amazing personal growth in the group, but we've had some really positive systematic changes. A couple of very quick ones I think of was there was an individual whose equipment had been cut off and that potentially due to that person's condition could have had extremely dire health impacts and due to the work that Peter and I were able to do with the assistance of QDN in Brisbane and interface with the agency here in Townsville, the NDIA who administer the NDIS we were able to see that situation rectified very rapidly. Also with CAPS, which is the continence aids, or something to that effect. With the NDIS rollout in Townsville, many people who were in receipt of that Medicare funded system were told they were going to have to wait possibly up to 6 months while they roll out on the NDIS, because that had been cashed out into the new program and many people couldn't wait. Again, we were able to feed that back into the system and people received those payments on time, or almost on time to tide them over until they were moved into the NDIS. Finally, the probably big systematic change that we've been working on now for many months and unfortunately yet to get quite the outcome we'd like and indeed need for many people here in Queensland is that of transport and the subsidy scheme the TSS. In Queensland when people move on to the NDIS currently, they are removed from the TSS program and so they lose their half price taxi card and unfortunately as the system exists currently, they're not in any way adequately compensated in their NDIS plan for that, which is having some rather dire effects in terms of people's ability to access their local communities. But we've been able to use, an absolutely essential service for anyone to be able to access their own community, absolutely. So we've been able to use our links with QDN and the NDIS and various different levels of government to work through this issue. We are still in communication with various levels of government at present to come up with both a short term solution and a permanent one, but watch this space on that one. We won't let it go quiet.

NEW SPEAKER: Maybe we could throw to questions and use that as a way to finish the session.

MICHELLE MOSS: I was just going to say and I think Daniel and Peter were being modest in terms of the power and the passion of the group around the taxi subsidy, because the minister actually has come to meet with the group several times, Mr O'Rourke to get that firsthand experience about what is happening on the ground for people with disability around the TSS and informing government in that way and that's a great example of the strength of the groups across the State to provide that lived experience to inform good decisions at a government level.

NEW SPEAKER: I'm not sure this one's working, I'm going to have to run around with this. We have a question here.

NEW SPEAKER: I do have a question, if any one of you can answer. As you were saying before, you're okay to do all disabilities, no matter what the disabilities are. I am hearing impaired, how well are people with a hearing loss catered for? I might come to a place like this and I can't afford captioning. Does the NDIS provide captioning?

NEW SPEAKER: So that was a question about captioning for people with hearing impairment, who would like to answer?

PETER GURR: We do and yesterday and the day before, QDN and the National Disability Insurance Scheme... I'm not sure, but I do know that we do at QDN and we also for people with vision impairment, we use a lot of sign and whatever they need, as well.

MICHELLE MOSS: And Shirley, maybe we can have a talk to you later about who to talk to in the agency 'cause we're not the National Disability Insurance Agency unfortunately, but we can find out the answer to that question.

NEW SPEAKER: We have one question down the back and then I'll come to you, Kevin.

NEW SPEAKER: I'm a care partner of someone who has younger onset dementia and very strong advocate, as he is, as well. I'm a care partner of someone who has younger onset dementia and he's a very strong advocate, as well. What I was going to say is we still actually feel very isolated and I didn't know anything about the fact that your group existed. We don't actually, we're from Brisbane, but our connection seems to be more national with Alzheimer's Australia and a lot of people don't even realise with dementia whether or not we fit into the disability area and I feel as if what we're trying to do is reinventing the wheel and I just wonder if somehow we can link up better.
I organise a support group and people are asking me for the information. John's just going to miss out on the NDIS because of his age, but there's so many people out there who are still not getting any help.

NEW SPEAKER: I will hurry up to the front.

MICHELLE MOSS: More than happy to connect and talk to you at lunchtime and I think there are lots of wonderful things happening in the community. Lots of great peer support groups and peer networks and it is about how do we work more effectively together, recognising that different groups have different purposes and different needs and visions, but there's great work that we can do collectively to strengthen that.

NEW SPEAKER: Daniel, did you want to say something?

DANIEL FLYNN: No, I'm good.

NEW SPEAKER: Just a quick one. I've been hearing a few stories of late about young people with disabilities in age care homes who are getting kicked out of the age care home and there's even one just down the road from QDN at Lutwyche that were doing that and they've been moved into State housing which is not even disabled access. Because NDIS won't be coming on board until 2019, has QDN had any thoughts...? I haven't seen anything on my emails come through for a while? Has QDN had any thoughts on how to deal with those people?

MICHELLE MOSS: Just quickly, because I know I'm holding everybody between here and lunch. QDN has been a strong advocate throughout the whole of the implementation process about how do we make sure that those people who are vulnerable don't miss out on the NDIS and people with different needs, whether they're homeless or at risk of homelessness, exiting the criminal justice system, child safety, young people in nursing homes. So the NDIA, or the department of social services have just funded four organisations in Queensland, QDN is one of them, to work in the southeast corner with people who are disadvantaged, experience additional disadvantage to accessing the NDIS. So we have started some conversations around young people in nursing homing. It is to work with people who are at risk of homelessness and all those other additional disadvantages that people experience. There are two organisations who are working in Far North Queensland to work with Aboriginal and Torres Strait Islander communities around supporting people and the community to access the NDIS if that's what they want, and also Imparo for culturally and linguistic diverse background.

NEW SPEAKER: We have one final question, if you can keep it quick, because everyone wants to go on lunch and we've got to prepare for the minister.

NEW SPEAKER: Hi, I did have two questions. One's really quick, are you coming to Rockhampton? Secondly, where do you see the carer's allowance and payment moving forward with the NDIS rollout?

NEW SPEAKER: I'm not sure if QDN can speak to the latter, but they can certainly speak to the former question.

PETER GURR: Under the NDIS, I had to find this out myself, because I'm a participant under the NDIS, my wife is on the full carer's payment. Under the NDIS, it doesn't affect your carer's payment. That's what we were told by Centrelink and that's what we were told by the NDIS. Now it is my payment for my care and my life. It is not my wife's. It is for me to get the care when my wife's not around, not my wife. So you've got to understand that, that it's the individual's package, not anybody else's and it only affects the individual for their entire life. That's another thing that people don't understand. Get it right first time, because it's for your entire life.

NEW SPEAKER: I think as you can tell from the questions, the NDIS is hugely complex, so please join me in thanking our wonderful speakers for shedding some light on that.

APPLAUSE

And also congratulate them for the great job they've done in setting up a really meaningful local support group that's making real change. So thank you very much for that work.

APPLAUSE

It's probably time we went to lunch. Thank you all for participating in these sessions, asking questions and listening so avidly. Hopefully we'll get to talk to you more soon. Thank you very much.

(Lunch break)

NEW SPEAKER: We'd like to move on for the afternoon sessions. I'm Steve Russell, I'm a member of the board of Health Consumers Queensland and we have three sessions this afternoon. The first one will be transforming culture, CHQ's ongoing engagement approach, that's children's health Queensland for those that don't understand the acronym and our presenters is Tania Hobson who's lead engagement officer with the Children's Health Hospital and Keren Pointon. Without anything further to do, I'll pass you over. (APPLAUSE).

NEW SPEAKER: Thank you, Steve. We would like to acknowledge the Bindal and Wulgurukaba people as the traditional owners of the land on which this meeting is taking place and acknowledge their elders both past, present and emerging.

NEW SPEAKER: Thanks Keren and thanks for the warm welcome. It's a great privilege to be invited to talk to you all today and I'd really like to acknowledge my colleagues back in Children's Health Queensland for their ongoing commitment to the work that we're doing and, of course, our consumers, some of which are on the front table here. Today we really wanted to give a little bit of a snapshot and talk about from a consumers' perspective what we're doing at children's health Queensland to transform the culture and drive improvement around patient-centred care. I'll provide an introduction to CHQ talk a bit about our consumer engagement strategy which was announced late last year, and talk about some of the ways that consumers are involved in our service. Keren is going to provide a perspective of a consumer, a family member of a child who was an end user of our service. Keren is a cochair of our family advisory council. Then we'd like to finish talking about some of our initiatives that have been led, in fact, by consumers in our health service that we're very proud of. We might have introduced ourselves a little bit. My name is Tania Hobson, I'm the executive director of allied health at Children's Health Queensland, a speech pathologist, but have the great privilege of leading a consumer engagement strategy. I connect people and I advocate for consumer and community engagement. We've got people at all levels of our organisation involved and doing great work. Keren, would you like to introduce yourself.

KEREN POINTON: So yes, my name is Keren. I've got two beautiful daughters aged 10 and 8 and our youngest 8 year old is what is commonly known as a hospital frequent flyer. Lots of surgeries, lots of medical teams, lots of complications and lots of very difficult conversations over the years and our family knows firsthand what a difference family-centred care actually makes. It's helped us stay out of hospital, it's helped us get out of hospital sooner, it helps us avoid complications and overall family-centred care has helped us have better outcomes. We are so grateful our family for the care that we've received and also know that things can be improved and happy to help make that happen. To do just that, I joined the Family Advisory Council a number of years ago and have recently taken on the role of cochair this year.

TANIA HOBSON: Thanks, Keren. Just a little bit to provide context about Children's Health Queensland. We are a provider of Statewide children's health services. We have a large hospital in Brisbane, Lady Cilento Children's Hospital that was opened in 2014. We also have a range of community health services that span the greater metropolitan Brisbane area footprint. We have quite a large child and youth mental health service, both inpatient service and outpatient services and we also have Statewide services. We've got over 4,000 staff and over 600 volunteers that volunteer their time with us I guess to better the lives of children and young people and their families.
I might just whip through these snapshots, some quick facts about our various services.
I was keen to just talk a little bit about our consumer and community engagement strategy that was launched late last year. It's up on the screen in very small font. You can download that from the website, but it is quite a broad strategy as you can imagine. Consumer and community engagement is such a broad area of focus, but some of the key areas that we're focussed on, I guess there's seven areas. One is around health

literacy, another is around digital engagement and how we partner with consumers in doing that and the voice of the child is a really important strategy that we're working on and, in fact, having some discussions with health consumers Queensland presently about how we can work together to deliver that component part of the strategy. Diversity is very important, so there's a focus on that and consumer and staff engagement. One of the key enablers to allow us I guess to meet the goals listed in this strategy is our affiliation with Planetree. You may ask, what is Planetree? A couple of years ago I asked the same question. It is, in fact, a tree found in America, but it is also the name of an organisation, it's an American based organisation. It's been going for about 40 years. It was founded by a consumer who had a poor patient experience in a hospital in America, but Planetree, in fact, is now has affiliation worldwide. I can't remember how many hospitals and health services, but there are a lot around the world. A couple in South East Asia and their motivation and their premise is around excellence in family and patient-centred care so we've recently become an affiliate with Planetree and we look forward to working with Planetree and our consumers and all the staff are on a journey to excellence in patient and family-centred care. I talked a little bit before about the level of engagement we have with consumers in our service and it's certainly at all levels within the health service, so we have consumers that sit on high level committees in the organisation. We have advisory councils and committees made up of consumers, both young people in the case of the great committee in charge of mental health which is Beautiful Minds, but also the Family Advisory Council among others and Keren's going to talk about that in more detail shortly. But we've also engaged and continue to engage consumers in various projects and a number of these projects are consumer-led. We'll be speaking a little bit later about the connections newsletter that's highlighted showcased out in the foyer and that's a project that was initiated by a consumer. In fact, the newsletter is coedited by consumers and, of course, Gary has joined us. Gary might say a few words later about his work in leading a Food for Families initiative at the Lady Cilento Children's Hospital. We do partner with Health Consumers Queensland quite a bit, not only in the education and training of the consumers and also of our staff, but in various strategic projects that we're working on together. I'll hand over to Keren to talk about the Family Advisory Council and importantly, her perspectives on being a consumer in the health service.

KEREN POINTON: Thanks, Tania. So our Family Advisory Council members are parents of carers of children who have firsthand experience of Children's Health Queensland services. Our membership is open across the whole State and we have many backgrounds, many experience. Some with young kids, some members with older kids, some members with foster kids. Grandchildren, as well. We have regional families and members from all different backgrounds, culturally as well. Diversity is one of our key strengths. We are unpaid volunteers and are often struggling children, both well and unwell and many members also have full time employment and significant work and other commitments. One common thing we're grateful for the care that we've received and are passionate about giving back and helping to improve services at Children's Health Queensland working with the organisation, with an emphasis on family-centred care. A very positive step in 2016 was being supported by Health Consumers Queensland with consumer engagement training. As Tania has mentioned, there are many examples and a growing list of consumer engagement and action at CHQ including increasingly consumer-led design. Next, I'm going to give you the consumer perspective on some of those activities and how that is going and the lessons that we are learning. So the consumer perspective, working with consumers is a given, but can often be tokenistic as health care providers struggle to find meaningful ways to collaborate. I'm sure many of you can relate to that comment, because it isn't always easy. So how to help with that? Well, small things make a big difference, so one of those is about setting clear expectations and that's not just for consumers, but that's also for staff. So for staff it's asking, what engagement are you after? Is it a oneoff piece of engagement, is it ongoing? How many meetings, how long are the meetings, how much prereading? A key ingredient for our Family Advisory Council was actually speak and meeting prep actually by the cochair or our executive sponsor, making sure that our speakers that were coming were very clear about what they were after from our Family Advisory Council, but also that we'd given them a heads up on the issues that we had and the questions we wanted answered. This is effective in making sure it's not just a talkfest, but we get real solutions and real momentum to resolving issues. For consumers, expectations are about are you there as an individual and your own specific circumstances, or are you there to give your feedback and discuss and raise systematic issues beyond the individual at the service department or organisational level? In regard to setting expectations, there's a lot of power in effective terms of reference and ideally, that as consumers we've had codesign of those terms of reference. For our Family Advisory Council we have a very good terms of reference that we've codesigned and having the mandate and support of the chief executive officer for Children's Health Queensland is very powerful. Another effective strategy to enable meaningful ways to collaborate is to apply family-centred care principles. What a difference family-centred care principles make in the delivery of health care, but they are also equally important when engaging with consumers. So, family-centred care principles, so respect and dignity. So that's acknowledging the unique challenges of the consumer and for us in the paediatric health setting. So having a meeting at 3 o'clock is probably not a good idea, because a lot of families are doing school pickup at that time. So it's being aware of that and not assuming, but asking consumers. Things like having meetings at a regular time so you can plan for that. Scheduled well in advance and documents well in advance. The small things make a big difference. Respect and dignity means engagement with us and not to us. It means asking, not assuming and it also works both ways so at our Family Advisory Council, we're updating our code of conduct to make explicit mention of our guests and presenters and how we interact with them or pose questions. You can imagine, we might have a lot of passion and emotion about particular issues and we need to make sure our advocacy is effective by how we pose our questions and engage in discussions so that it's not intimidating or confrontational, that it's effective and collaborative. Information sharing is another family centre care principle. For example, consumers receiving the same report at the same time as other participants and an effective way of allowing that to happen is using confidentiality and code of conduct agreements to support that. Inclusion in difficult and challenging conversations is actually a sign of success for our Family Advisory

Council. As is when there's ad hoc and spontaneous conversations where executives and leadership staff members come to our meetings and discuss ideas that are not fully explored or fully endorsed, because they're seeking early feedback from us as consumers. Also, when people come to our meetings, but stay after they've done their bit because they want to continue to listen and continue to engage. These are all signs of success about information sharing. Another family centre care principle is collaboration. So that's making sure there's a perception of open and transparent engagement. Decisions not outside of meetings, but decisions and actions and discussions that are documented and it's listening and embracing feedback, no preconceived outcomes or ideas. It means resetting your thinking and be willing to codesign and not just come in at the end with an already designed process. The final family centre care principle that is equally relevant in health care as well as consumer engagement is participation and partnership. For example, consumers having input to agendas and discussion. For our Family Advisory Council, we own our agenda. We collaborate and partner with Children's Health Queensland about the agenda and who's attending, but it is still our agenda and we own it. Again, small things make a big difference. Helping participation can be as simple as a clinician who might be chairing a committee or a working group spending that 5 or 10 minutes before the meeting or after the meeting with your consumer representatives and making sure that they understand the language, the acronyms and seeking their input that might then be drawn out at the next meeting. Participation is also helped by having more than one consumer so that they have support and backup and at CHQ that's a key strategy that is also used. At the Family Advisory Council we actually have a member duty register of who does what, who looks after the issues and action calendar our share point site, our annual report group. It is about getting participation amongst our membership, spreading the load and getting engagement, which helps for succession planning. Participation and partnerships about valuing the skills and abilities of your consumers, we are not helpless parents, but we are here to help you and bring amazing lived experience and often a lot of professional and other skills that are there to help the health service. Changing that view of who your consumers are is a massive way to make meaningful collaboration. The third point on the slide is smart technology use and using that to help inclusion. This year, our Family Advisory Council has codesigned with the Children's Health Queensland IT department a share point site, which is a website that you can collaborate on. This has been transformational for our Family Advisory Council as it is having a CHQ supported and endorsed document storage and collaboration tool has been so helpful. We use it to store all our documents. It helps us avoid email spam. I'm sure many of you on committees can relate to that. It's our single source of truth and it doesn't matter who is our CHQ secretary support, who is our executive sponsor, who is the cochair of our committee, or who our membership are, we have our history that is maintained and our processes will continue hopefully seamlessly. Video conferencing is another smart technology used that helps support better inclusion and we have a number of regional members who dial into meetings using video conferences. But being smart about technology is also being mindful of when it doesn't work and it's not the best solution. We have a member who prefers teleconferencing, because she has young children. Our meeting's at 5.30 to 8.30 and being on a teleconference rather than a video conference means she's much more able to still participate and hear, but run around, do baths, manage children, multitasking, how to translate feedback in real terms from consumers into change for health care organisations, how to transform. This whole forum is about transforming culture. Well transforming is more than change, it's to change markedly, there's no turning back. Number one, early involvement is key and ideally consumer-led or codesigned. That's when powerful change happens and to do that, you need clear and established channels for wide feedback that you capture in multiple ways, like recruiting consumers in working groups and committees at the planning and issue discussion phases that enable consumer-led design. CHQ is doing that with a central process to engage consumers in their patient safety and quality unit. One of the other challenges is how to systemise using wide feedback. That feedback to patient safety and quality staff, that feedback to social work, those patient surveys or nurse groundings. It is that early engagement at design phase is a first and priority step, not just what we call a spell check at the end. When you see it happen, you see the lightbulbs go off by leadership and clinicians who say "Why didn't we do this earlier, because we get a far better outcome?" Number two, to transform and make real change you need to make and measure feedback. Reporting on those targets to make them accountable and make them visible, so at Children's Health Queensland there's a number of what we call eye care projects which are innovation, change and redesign excellence projects and they have a target of 50 per cent consumer engagement, for example. So another key thing is rewarding and acknowledging and promoting the people who are doing it well. In fact, the people who are doing consumer engagement well should be the people that do rise through the ranks. You know your organisation is transforming when your CEO talks about family centre care principles and consumer engagement all the time. That message flows down to the executive leadership team and so on. It is also very important to have regular feedback to consumers on how their participation has positively contributed to CHQ service improvement, so closing the loop, tell us that you have heard, you have listened, you have acted and this is what has changed. Oh, and thank you for your help and input. Third point, to transform and make real change, policies and processes have to change and that's about embedding changes by systemising them, in policies and processes that are practical and real, not theoretical. Of course having consumer input into that is very important. It may also be writing new policies or guidelines. Our Family Advisory Council has raised the issue of having a guideline about recruitment. Our committee members have been on recruitment panels for a number of years now, for a number of senior positions at Children's Health Queensland, but having a guideline so that ideally for certain level of leadership roles or consumer basing roles that there's always a consumer on that panel would be a great strategy we're investigating so it's not just reliant on a particularly family centred care, consumer engagement recruitment leader, but it happens because the process is embedded in the system. Finally, to transform and make real change, training is key. That's about supporting staff in a new way of working so that new process for whatever initiative happens regardless of which staff member is working, which ward you are on, which service you're interacting with, which department. And that means supporting consumers with training, too. For the fact we actually have a buddy system for all our new members, where continuing members support the new members, with support and training. At Children's Health Queensland, the patient safety and quality team have engaged with health consumers for training of both staff and consumers on consumer engagement which has been enormously powerful and helpful. These are some of the ways to translate feedback in real terms into change that are helping Children's Health Queensland transform. Next, Tania will speak to a couple of examples of consumerled initiatives at CHQ.

TANIA HOBSON: Thank you, Keren. I wanted to reinforce another key initiative that relates to consumer engagement and family and patient centred care is our work that we have started and will continue to progress around integrated care. I know a number of hospital and health services are doing this and to me, integrated care is all around putting the patient and family at the centre and connecting them into different hospital and health services in working with GPs, private organisations, NGOs and, of course, through the primary health care network. So that is another exciting initiative. We were talking before about some consumer-led initiatives, now Kirsty is here. Kirsty is a member of the Family Advisory Council, fairly new member of the Family Advisory Council. Can you stand up, Kirsty. Kirsty was the instigator of the Connections newsletter featured here and also outside and Kirsty with another consumer Hazel coedit this newsletter. It's a newsletter written by consumers for consumers. If you want to subscribe, jump on to our website and you can find the link there to subscribe. We've got a really, really good subscription rate and our hit rate is between 60 and 85 per cent which I'm told from my media and comms department is outstanding. Thank you Kirsty for all your work, and Hazel as well. I don't know if Gary is still here, but Gary Hondo is another member of our Family Advisory Council and prior to him starting on the Family Advisory Council, he was engaged with Lady Cilento Children's Hospital and essentially led this initiative around Food for Families. We're using a voucher system now for family members to be able to purchase nutritious homestyle meals at an affordable price and importantly, this allows family members to stay with their children or their siblings at the bedside and also to be able to eat together, so it's a tremendous initiative and we really thank it's ongoing, but we thank Gary for all his support in doing that. So that's essentially... I know we're running out of time, is the conclusion to our talk today. It is a journey, consumer engagement is a journey. We feel that we're well on the way to that and look forward to coming back potentially next year or the year after to give you an update. Thank you very much.

APPLAUSE

NEW SPEAKER: Thank you, Tania and Keren for a most informative presentation. We've got time for about three questions. Are there any questions from the floor at all?

NEW SPEAKER: Hello. I just want to again thank Gary for the initiative of the Food for Families project. It highlights something that has been a concern of mine for a little while as to how come there are people in the departments and in the service provider industry and so many other areas and these are professionals and it takes a consumer to come up with such a simple idea and it shouldn't just apply only to children, into the children's hospital. It should be something that's across the whole of Australia. Every State Health Department should be incorporating that as a standard practice for people and giving them the opportunity to stay close to the bedside of people and if you look at the elder population, the aged population where perhaps the carer can't drive as well and has to catch two buses and that's the person who knows the person in the hospital better, so it's something that has to be addressed across the board. Thank you, Gary.

APPLAUSE

NEW SPEAKER: Any other questions from the floor? In that case, thank you very much Tania and Keren for a most informative presentation. Look forward to seeing you next year. Thank you.

APPLAUSE

One moment and we'll organise our second presentation. Our second presentation for the afternoon is from the Caboolture and Kilcoy Hospitals and Woodford Correction Health Service and our presenters are Suzanne Michaels manager, integration and engagement, Jurina Demaine, consumer representative and last but not least Lance Le Ray who's executive director and director of medical services Caboolture, Kilcoy and Woodford Correction centres. Thank you very much.

APPLAUSE

SUZANNE MICHAELS: My name is Suzanne and this is Jurina our consumer rep here and we've brought along a token executive today which is Lance, so here's here just to look pretty, but he will say a few things. As you can see, is it okay if I stand here, I tend to move when I'm talking. As you can see, our presentation today is on culture change and specifically looking at the role of individuals, but also individuals working as a collective and we've got this image here talking about driving cultural change needs multiple hands on the wheel. It is not up to Lance, it's not up to a consumer, it's not up to one person who has that portfolio to do that work. It has to be a collective and we have to be going in the same direction and work together to make it work. I'm going to take you on a journey today, because we're talking many hands on the wheels, talking about a car journey. I'm taking you through the journey of our culture change. My background, I'm not a clinician, I'm also not a change person, I'm not a culture person, but and I know we use a lot of acronyms in health, but there was one that I really liked and it was ABC and it basically says as you can see attitude plus behaviour equals culture and I suppose that's what I've kept in mind as we've put these programs in place. It's not just about what we do, it's the way we go about things. It's what we believe, it's what we say in every single interaction. It's the way we operate that will have a cultural impact at the end of the day. Just going to take us back a few years and I'm going to share, I'm going to ask Jurina now just to share her experience of what it was like to be a consumer. She's been involved with our organisation as a patient 15 plus years and she is an active consumer in the Breast Cancer Network and so had been actively trying to get involved in Metro north and more specifically Caboolture Hospital. I'm going to let her share what that experience was like before we kick started thing.

JURINA DEMAINE: Actually, Suzanne it's closer to 20 years. My introduction to Queensland Health and Caboolture Hospital was in December 1997 when I was diagnosed with breast cancer, so I'm coming up to my 20th anniversary, so I'm a thrive, not a survivor, just to get that right. Things were very different back 20 years ago and I was very unhappy with the things that happened to me in my first experience of the hospital, but I had two caring and compassionate registrars and a thoughtful nurse who kept me on a level of sanity that was quite handy, because I was falling apart. Since that time and because of my experiences, I've been actively involved with supporting cancer patients and with advocating for change in our local hospitals, particularly when our little hospitals don't have the same standard of care that other hospitals in our health district do have. That just irritates me, but my efforts were generally ignored and it was like fighting uphill all the time. You were knocking on doors where nobody was home, but the lights were on. You were looking for windows of opportunity and there was blank walls of indifference so it was frustrating. I wrote countless letters and emails about various services that we needed and most of the letter s were never answered. It was really frustrating. The thing that made it harder and more frustrating was I wasn't acting alone. I was writing on behalf of my support group with over 400 members and I was supported by a lot of well known and important community groups. There was Business and Professional Women's Association, Dragons Abreast, some weight loss groups, the sports club and so why was I being ignored?

This is not just my issues. This was community issues, so I just didn't understand and that was advocacy over the last lots of years. Thank you.

SUZANNE MICHAELS: Thank you Jurina, and Jurina will talk again throughout the presentation and share her journey, but I'm going to ask Lance to share a few words. Lance and I came a couple of years ago into the organisation so I'm going to get from the executive's point of view about what he thought about where we were at.

DR LANCE LE RAY: The standard of care was not uniform, that some parts of the organisation had it right and other parts did not. You could not say with confidence or conviction that the expectation was of person-centred care. There was a willingness to consider and to explore change, but by and large people were stuck about how to actually do that. None of us are particularly happy about the way it is now, how do we move it forward? So there was good intent, pockets of good practice, but it was an organisation that was stuck. So we had to shake it up.

SUZANNE MICHAELS: Absolutely, thanks Lance. I know Lance just said about pockets. We had brilliant projects happening at the time. One of those you can see outside at one of the learning pods with ematernity site. We didn't have a uniform approach or an overarching commitment. We found out... I suppose we knew it was coming. Caboolture is a burgeoning area. We're about to grow the population by about 40 per cent in the next 510 years. That's an extra 6080,000 people accessing our services and we have a very low socioeconomic area with a lot of psychosocial issues. High poverty and twice as many young mothers under 20 than the national average so there's a lot going on and we knew we weren't quite hitting the mark as far as patient-centred care and we knew if we were going to grow to be the hospital that the community needed in the future that we really needed to work with and understand what they wanted from us. So that's where we had a jump start, that's what kicked us off. Said right we've got something we need to do now, so that started the journey back in 2014, 2015. So start we, we went we need to start talking with the community. We've spoken with individuals, we need to know what the community says. We held a workshop and invited people from the local community to come and talk to us about what we had, basically their experience of service and what they envisioned us being in the future. Interestingly, the people invited to that workshop is people who had made complaints against the hospital. We invited them in, we had strong supports in place. We had the staff trained up, we had social workers, psychologists, people there to allow people to share their experience, for them to do that in a safe space, but then to have facilitators who worked with us and then to guide a conversation so they walked out thinking that what they had said had made a difference and it would make a difference in the future. We did a lot of dreaming and discovery planning about where do we want to go, give us the idea of what you want to see. So around that time, we had these workshops with them. We did staff workshops as well and got lots of awesome ideas from them and around that time there was these words that were being thrown around. We were talking about, how are we going to do this? I think it was one of our consumers who said this is not about us telling you what to do and it's not about you telling us what to do it's just about us doing it together and this idea of caring together was born. So this is actually the second iteration of our caring together initiative or program. When we first started it was mostly around family and patient centred care and we would say that caring together is our commitment to partner with you so you feel heard, valued, supported and respected always and that's the values we had in the way we approached our patient and family centred care and initiative engagement. This has moved beyond in the last year or so, moved beyond being a program to just business as usual. Caboolture Hospital is improving the health of our community by caring together. After all those staff workshops, community workshops we went okay, we know what we want. We want to go from where we are now, we want to be the most patient and family centred hospitals in the country. We also realised in talking with our staff that to do that we had to be an employer of choice. We had to take care of our staff so well that they were so happy that they then took care of our patients. We knew that and heard that from consumers as well. Take care of your staff and then they'll take care of us. Okay, so we knew the destination. We knew where we wanted to be and we went "How do we get there?" We've had a conversation with the Australian Institute of Patient and Family Centred Care so we went to them and said do you guys have a framework or a structure we can use, because we want to do this, how do we get there? They said we don't have anything to detail a step by step process of how to get there. We said okay, can we develop one with you? Sure. We'll do all the work, they said sure. Over the last couple of years that's been a project that we've had ongoing on the side. I shouldn't say on the side, this has been what's driving a lot of our work. We had our caring together framework and you can see on the diagram on the left, we have the caring together values around the outside and then we've identified six key areas that need to be influenced in order to deliver patient and family centred care. Learning, leadership, service delivery, engagement, service improvement and the environment, and we kind of had that as a broad idea and then we actually have not done a lot of work. Literature reviews and took feedback from consumers and you'll see on the left, your right, we've actually developed that into a framework. Now when we say we need strong leadership to deliver patient and family centred care. What does that mean? We have a list of things that means that's what we're aiming for there and we're slowly finalising that and getting that ready to share with people. At the end of the day this is just a piece of paper and the idea is that we'll get to a point where we can share that with other people. We wanted to make this real and see if it was something we could actually do. Over the last couple of years we've been doing a lot of work about embedding this framework, testing it, seeing if this would actually work and what we've done, the process that we've taken is that we have a caring together governance committee, a committee within the hospital that has everyone from executive down we've got doctors, nurses, operation staff, admin people, anyone care to be involved and Jurina sits on that committee. We have a consumer network. I know a lot of people have consumer networks. We went about ours a little bit differently. We set up the consumer network so that when consumers are recruited or found or brought into the organisation they are brought into the network and the network meets once a month as a group and the idea is that they get to network, learn from each other. Remember, there are about a dozen people who are on that and they are kind of integral. They come into the network and based on their interest and experience, we link them up with a committee or a working group or another project where they say "Hey, I'm interested in that", but we also say, what's your interest, what's your experience, what would you like to get involved with? Then we find projects that align with those desires. We have made sure that the network has a clear up influence. We make sure what they're doing is not tokenistic. A big part of what we do within the network is educating the consumers as well, and I will say that one of the most valuable parts of this is constantly having that executive support. We've had executives come and talk to the network. We have people from across the organisation come in and talk to them. I just want to highlight, I've highlighted there it is about a partnership. We treat the way we approach it is consumers are the experts in their lived experience and we try and make it very much 2way. Of course we'll have things we ask of them, but we say what do you want from us, how can we support you? We get involved in lots of activities, so basically I'll touch on the way we do it is at each network meeting we have the first half where we have a guest speaker who comes and educates the consumers on a particular topic and we spend the second half doing a workshop on a project that's happening within the hospital. We do have consumers who now sit across all of our major committees and working groups. We are a fairly small hospital, but we've managed to integrate people into most and now most people will say hey, we're starting this group, we've got a working group, can you get us a consumer for this group. If we don't have one within the network, we'll reach out and find others. This is valuable for consumers and also staff, simply having someone sit at the table, be that body so we're talking about budgets and infrastructure, the next person in line is the consumer, what are we doing, how is this going to impact our patients? One wonderful thing that happened last year, we had our deputy director of medical services who sits around Lance and he said from now on we want a consumer on every interview panel for every senior appointment within the hospital. We've managed to achieve that over the last 12 months and it's been a phenomenal experience. Not only for consumers who they think, a lot of them felt very fish out of water. Who am I to sit on the interview panel for a senior staff surgeon? We said to them, you're in there not to look at their experience, but purely to think, would you want this person to be your doctor? Would you want them to be your nurse?

DR LANCE LE RAY: My observation is that clinical staff can be beguiled by the CV, you can have an impressive CV from an eminent person, but the consumer person on the panel is more likely to out the dickhead, the one you don't want.

APPLAUSE

SUZANNE MICHAELS: Absolutely, and that has happened on more than one occasion. We've had panels of senior leaders who will say, "What about this person?" And they'll turn to the consumer and say, "What do you think?" And they'll say well, they didn't really answer that question, or I felt really uncomfortable with the way they were talking about their patient and then the staff will say "Oh, I didn't get that, oh, you're absolutely right" and it's been integral for them coming up with their list of... what do you call it? The short listing of who's going to be recruited and it has been a phenomenal experience, because now we're getting the right people. That's what driving the culture, getting the right attitude and behaviour is about getting the right people and that's one way we've been doing it that we've found works really well. For us, building partnerships is really about integrating, getting people out and into every opportunity that we have. Our consumers are building relationships with people. We have people aligned to ED, or people aligned to outpatients. People who are our spokespeople within the community within Caboolture health care alliance. She is little, she's this big, gorgeous, Lenny does around every Thursday and does patient surveys. She likes talking to people and she is loved by our staff now. When they see her coming, they welcome her into the ward. We love to hear what people have said at the end of the day and she is now one of our most desired people around the hospital. One of our big projects we did was the Ward 3B. For anyone here last year Christine Bryant shared her experience of being a consumer on that and that was a codesign project, building a ward with a secure unit for people with dementia and delirium. She had brilliant ideas to share within that design phase and things that changed the design of the ward. One of the key things she wanted was contrasting colours within the toilet

and when she saw it she actually was teary. This new ward that you've got is worldleading and it's encouraging for us and for the patients and the families we have coming in now, knowing it was designed for them in mind, because we had a consumer involved. One of our big areas of focus around driving culture change is education and I know it's a big deal for a lot of people. We always talk about get consumers involved in education. We've taken a different approach. Of course we talk about consumer engagement, patient centred care at orientation, but within the framework that we've developed we use the words immersing staff in consumer perspectives so instead of having one course on consumer engagement patient-centred care, we look at the yearlong program for education and we identify which of those educations that's happening can we get consumers in, get that voice into the ones that are already planned. You can see, obviously new doctor orientation we did one hour talk about lived experience around handover. For example, I'll just show you one of the ones we did was this one down the bottom here. One that I saw on the calendar, there was already a doctor prepared to talk to interns about treating people with depression and anxiety. We have a couple of consumers who've got lived experience, can they come along?
We ended up talking with the doctor ahead of time and it was brilliant. It went from her sitting there telling them what to do and what they should look for to having an open conversation between the consumers and the new interns about their experience. This is what I'd want from a doctor and what I hope you'd look for and it was hugely valuable. And now we have, building that value as the consumer network and getting those people involved, we have people coming to us now saying hey we've got this coming up, who have you got, who can we get involved? Rather than pushing people on to our staff we've got them coming and saying, “Hey, how can we get them involved?” I will touch on very quickly, part of this whole program has been about getting our staff engaged as well and getting them involved in patient family centre care and making it relevant for them and finding the value in it. There's a couple of projects we did last year, the Tribal Challenge and Kindness in July and that was helping people to think about how do they connect with their patients, what else could they do in their local areas? We've had awesome projects come out of that, including the one

down here, we've designed a whole new handover document from ED to the wards and that's been with patient involvement, because they identified that. How are you doing patient and family centred care, where are your gaps? Let's do a project around that, and they've been able to do that. I might just hand over to Jurina now. I've talked from our point of view, being the person on the ground, the staff member doing this day to day. I'm going to hand over to Jurina just to share her experience of what it's been like to go through that change process with us.

JURINA DEMAINE: Well, I must say, along came Suzanne and so this little powerhouse of enthusiasm and determination just swept us all along in our wake. It was really easy, we didn't have to worry about anything, she sorted everything, but her focus initially seemed to be entirely on creating meaningful partnerships between staff at all levels and the consumers and we all felt that and we all felt she needed us to be real partners and not just tick a box and that was really important for a lot of us who'd been battling to get into the system for a long time. Things have changed and the difference at Caboolture Hospital is palpable. The hospital is now in just over one year I might say, she's done all of this in a year, in just over a year, the hospital is now a truly friendly place. A place where you feel welcome, so she stole my thunder, I was going to tell you some of the things we do. The whole face of the hospital changed, because we redid some forms, documents, signage, posters and the hospital just looks different with all these new posters and nicer colours and neater arrangements and things like that. You didn't get that one! But we suggest changes in building design and policies and also review some education stuff, staff surveys. We've had people speaking at staff forums, as well. So new ideas and new projects just keep on emerging, so we're not losing any interest, we're actually getting quite excited. We're also reviewing consumer complaints and learning about what sort of complaints come in and how they're handled and what the hospital does and once you know what kind of complaints they're dealing with and the numbers you have a whole new respect for how all these things are managed. At this stage, we all feel free to express our opinions, make suggestions, ask questions, report issues and join in discussions. Now we really feel that we are respected team members and that our opinions really are valued.

SUZANNE MICHAELS: Wonderful, thank you, Jurina.

APPLAUSE

I know we're running out of time. I'm going to end on this last one here. We're going to take a minute or two to talk about the things that if we were to turn around tomorrow and say as the dedicated person, as the consumer, as the senior leader what can we suggest? These are the things we're still trying to do, but what could others do?
I might hand over to Lance just to share his thoughts.

DR LANCE LE RAY: First, invest emotionally. This has got to matter to your executive group. You've got to invest intellectually, how are we going to do this? Culture doesn't just happen. You have to seek to influence, what are you going to do that's going to change the way people think now and in five years' time? You've got to invest in people, you've got to hire the right people, you've got to be prepared to say to clinical staff, no, I'm not going to put that money into a nursing position, I'm going to put this into this other position, because it will ultimately be greater value.

SUZANNE MICHAELS: No pressure!

DR LANCE LE RAY: I guess the other thing is you've got to be in it for the long game. Two and a half years I think we've been going now and we're sort of somewhat along the pathway. I don't think you can buy in a solution, I don't really believe that personally. You have to come up with a bespoke solution for the organisation you're in. I don't think you can buy a product off the shelf that will transform your organisation, because the transformation has to come from the bottom up.

SUZANNE MICHAELS: Thanks, Lance. Jurina, do you want to share your last thoughts on what people can do?

JURINA DEMAINE: If we're looking at what we need now from health professionals, that's where I'm aiming. A staff member once said to me 'cause I was trying to get change, we are the professionals and so I thought well, hello, I actually had quite a good professional background myself in my past life. Noone ever checked up to see what I ever did. What I would like all health professionals to recognise is that every patient they see is, in fact, or was a professional in their own chosen field and once that can be appreciated by the professionals in the medical field, they just have this vast unlimited source of information, intelligence and experience that they can actually draw on and learn from which would be great. One other message for all our health professionals is, you must realise that one day, you will be the patient.

APPLAUSE

So what do you want your health service to look like when that time comes, because it will come, and what kind of treatment do you want? Because if you start now working towards that vision of your ideal treatment, by the time you need it, you will have the best ever treatment in the best health facility in the world. Thank you.

APPLAUSE

SUZANNE MICHAELS: Thank you, and just to finish, I was just going to say one thing. I've got this thing up here that says yes, if you're a Queensland Health worker and someone says to you hey we want to get a consumer involved? Just say yes, work with it. If you're a consumer and you're wondering about doing it and someone says "Hey, would you like to get involved?” And you think it's scary and big, just say yes. Jump in and do it. A lot of it is just learning along the way. That brings me to the end. Thank you. Is there any questions?

NEW SPEAKER: Just before we go to questions, I think that was a most powerful presentation and right on message in terms of power and passion and cultural change. This is the direction we really want to go and we had the power presenter, we had the thriver and the “tell it as it is doctor”.

APPLAUSE

Thank you very much, and it's certainly a facility that I wouldn't mind seeking treatment in. There's a question at the back.

NEW SPEAKER: Did you do any training and did you have consumers attend?

SUZANNE MICHAELS: We put the entire workforce through CAPS, so communication and patient safety. It's a program that's come out of Metro south. If you have a chance to do it 100 per cent you should do it. It's an 8hour program. We put almost 1200 staff through it I think and it's just around fundamentals of communication and things, but we noticed for the first time ever that after several months of staff having done CAPS that we actually for a couple of months communication wasn't one of our top complaint within the hospital, but it was phenomenal. Have you done it?

NEW SPEAKER: Yeah, I did it as a trial 18 years ago.

SUZANNE MICHAELS: I think the timing was just off for that, so we've worked through CAPS, so CAPS was brilliant, but it's a 1day program and we worked with the developers of CAPS and we've developed CRASH and that's a 4hour program that's part of orientation and our consumers will absolutely be doing that. So yeah, thank you. It is about educating our consumers so they're hearing the same thing that our staff are hearing.

NEW SPEAKER: We've got time for one question.

NEW SPEAKER: Actually, it's not a question, it's advocacy. As a frontline worker, we are trying as well to improve the hospital health system. We are a board also and as a consumer, I am a witness to that, thank you, so your voice has been heard.

SUZANNE MICHAELS: Thank you.

APPLAUSE

NEW SPEAKER: Perhaps just a further sign of appreciation for a very, very positive presentation. Thank you again.

APPLAUSE

Our final presentation this afternoon is from the Metro south hospital health service and it regards evidence from a systematic literature review from Griffith University and our presenters are Carolyn Ehrlich and Faiza Elhigzi.

APPLAUSE

CAROLYN EHRLICH: So my name is Carolyn Ehrlich. I work at Griffith University and what I'm presenting with you this afternoon is work we've done in conjunction with Metro south health service, but also I'll be bringing in work we've been doing with Health Consumers Queensland around all of the language and the understanding of what's meant in some of these terms with consumer engagement. What I've got at the end of the day is trying to bring together a lot of the language and the things that we've heard in a way that perhaps shines a new light on a couple of things I'm hoping. I guess what we know is that consumer engagement, there's certainly been a shift towards that language of consumer engagement and involving consumers much more in health services, in health research and in all of the components that are associated with the delivery of health care, but there's a fair bit of jargon involved with that. So we use words like consumer engagement, we use consumer involvement, we use consumer advocacy, we use public participation if you come out of the UK. There's consultation, collaboration, consumer-led, codesigned, coproduction... what are some of the others? But there's lots of language that goes around that and the challenge with using language when we do that is that there's two challenges. One of them is that if

I use a particular language that's coming from my understanding and you use the same language coming from a different understanding we think we're talking about the same thing and we're not. The second thing that comes with that is this language that we're using often becomes what somebody described as virtuous. It's got this positive feel about it so we must all be doing it and it must all be good if we're doing it and it's not always all good and we feel as if we can't challenge some of the things. I'm not saying that consumer involvement is not good, I'm just saying that some of our understanding needs to be challenged. So we're assuming a couple of things, we're assuming it's a natural progression in health care. It's a progression in health services and the delivery of health care and also a natural progression in research that's related to health. So moving away from I suppose there's a number of things we do in research, but getting consumers more involved in research. That's what the first part of this presentation will be about and once I'm finished Faiza Elhigzi will introduce herself with what she's doing. We also assume that more engagement means better quality, cost effective and highly valued health care and I'm not challenging those assumptions are incorrect, they're probably quite valid, but we do know that it's an experience when we're talking about consumer engagement, it's not something that is done and we've heard that repeatedly today sorry, that it's an experience. The thing that I find interesting when I read the literature about engaging consumers and all of the language that goes around that is that it seems to me that when we're talking about engaging consumers we're coming from three different and sometimes not easily compatible traditions. One of those traditions is the civil rights movement, it's moral obligation we should engage consumers, nothing about me without me, it's a definite way to go and it's important, but the other thing that happens when we're talking about engaging consumers and the work that we do with engaging consumers is the sense that there is a) personal responsibility for some of our own health outcomes. I'm clearly overweight, it says to me that if I have diabetes, if I have a bung knee which I have, I've got some responsibility myself for what I do so there's some of the work we do with engaging consumers is about that personal responsibility for our health and our health outcomes and whether we can meet those expectations or not. The third tradition that comes in is much more I guess from the service perspective, but it is that we need, a funder's perspective is we need to have health care that is cost efficient, it's got to be effective, it's got to be high quality and safe. For all of those reasons, consumers are engaged in health care, health services and health research. And I've mentioned those three things now. There's the three different areas that we're looking at so it's like multiple layers of an onion when you try to work through that. We engage consumers in the actual care of health that's delivered. How do we work with that? We're looking at health services and that's more tangible and less tangible elements of service provision rather than the experience of care and then health research, we're looking across all areas of health care and health services. We'll work from qualitative research which is what I do and engaging consumers on a very practical level to multinational randomised control trials that you see of new drugs and new things, so we engage consumers across a plethora of areas. So what does that mean? And the next new slides are about engaging consumers in research and every time I look at these slides I realise I can change the word research to adjusting to health care and health care services. I think for these slides they're interchangeable. The limitation is that I've looked at this from the perspective of health research and there may be other things that are also important beyond the health research sector. But when we want to involve consumers in health research, we can involve them at multiple different levels of health, or areas sorry, and we can involve consumers at designing, their interest in research topic, what is interested to consumers and what should be being researched, rather than what is important to researchers and what do they want to research? There are advocacy organisations, the Cancer Council, for example, can be involved in funding research for cancer at all different levels, so consumers are involved in that. We can involve consumers in the project design and management. We can actually involve consumers in doing research, so collecting data, analysing data, interpreting data, writing it up. We can involve consumers in disseminating and implementing findings from data and also in evaluating the impact. That's not how we tend to think about research often, but of the bulk... especially with randomly controlled trials, it's about consumers participating. They're the subjects on which researchers put their view and do their research, but we must be mindful we can engage consumers in all sorts of areas. How do we do that? I guess the thing about that is that we need to... and again it's engaging consumers in all areas of health services, we need to have a legitimate involvement process. It needs to be authentic. It can start with consultation, it can be collaborative or it can be consumer controlled and consumer led and I've heard those words used today as well. From the perspective... and I suspect this is true of non-research areas as well, but from my perspective there isn't anything wrong with consulting consumers for research. There isn't anything wrong with only asking consumers to participate in research, providing that you're not pretending you're doing something else. So it's really important if you're saying that you're going to consult with consumers, don't assume that you're collaborating. Don't pretend that you're doing it and that's where that notion of tokenism comes in, is when as the more powerful people in the room generally we're saying we think we're doing this when, in fact, we're not. We need to invite diverse participation. We need to manage power dynamics and we need to align our research with the purpose of involving consumers and how we go about doing that. The other thing that's important about consumers, and we talked to a number of consumers in Metro south and we also talked to some of the clinical researchers in Metro south and what we found is that there's a general understanding that engaging consumers is part of best possible care and that's inarguable, it's absolutely true, but we also know that consumers aren't always engaged early in projects and we heard that just from the previous speakers. You need to engage consumers early. You get better outcomes if you do, and the other thing is there's often different priorities between researchers and consumers and we need to understand that and have a look at that from time to time. One of the examples that was given is for some people, for example, people that might have had a spinal cord injury if they're looking at research what they want is a cure. If they were to give all of their money up for research, it would be to be for a cure rather than care for somebody who has a disability as a result of that. It's managing those boundaries and those tensions between what's important and what's not important that can often be very challenging. What consumers told us when we were talking to them is that we need to focus on what's important for consumers. We need to understand their expertise and we needed to understand that tension between being an expert consumer, patient, carer, whatever language we're using and losing the native consumer perspective. It's important to understand what we're looking for and I think that probably goes across to health services and what we're doing there, as well. Patients become experts or consumers become experts in their role as consumer consultants, consumer advocates, whatever language we're using and there is nothing wrong with that. We absolutely have to have expertise in our consumers, consumers need to navigate health systems that are quite complex beasts even if you work within them, let alone when you come up against them. We also need to understand who we're expecting consumers to represent or what we're expecting them to represent. Are we asking them to represent their voice and their experience, or are we asking them to represent the voice of multiple people with a similar experience, and what does that mean for how as researchers or as health service managers we interpret that? It's interesting, consumer can mean anything, it can mean me as an individual, or consumers can just mean everybody, so the kind of view that we're looking at from me as an individual as compared to me as a representative of everybody is very different. It's interesting to try and understand that perspective and to be aware of what we're thinking when we're doing that. We also need to consider convenience. It's sometimes very convenient to go with the people that we know all of the time and sometimes it's more difficult to engage with people who we don't know how to engage with well, and so how do we engage with them to do that? Researchers, that's me, that's what I do.

We come from a research tradition, so we have our own perspective and that's where it can be often quite challenging to work together. I've said I come from a qualitative research perspective, what does that mean? Probably nothing to most of you and that's quite okay, but we have our own way of looking at things. We come from a disciplinary focus, so nursing is my background. Whatever I do will come from a nursing focus. We have individual preferences and idiosyncrasies just as everybody else. We have particular lenses of looking at things and particular motivations for why we do things and somehow we've got to match all of that together with why we need to be involving consumers in our research endeavours, how we're going to do that, when we're going to do that, at what level we're going to do that, over what time and how we're going to manage it, so it's quite a challenging process to manage just that interaction between the consumer, or consumer groups and researchers doing that. But at the same time there are some quite influential structures that influence what we do and funding models is a big one of them and that happens in health care services everywhere. There's also organisational cultures and heritages that we inherent, so within Australia the group of eight universities have a different culture than some of the other universities do. I was talking to somebody yesterday who did some work with nursing students that were coming out from a particular university and they have a different perspective than the nurses from other universities or students, so we have university cultures that we need to work with, as well. We also have different purposes for engaging consumers. We also have different job descriptions and we also have different research support, so all of those factors together mean we end up with a machine that's not particularly well oiled or smooth and we think it is, but it's not. It's a continual progression. It goes forward and backward regularly. We take one step forward and two steps backward often. There are multiple interacting factors. There are different timeframes, different rewards and different motivations that are involved.

We need to have a clear vision about what needs to happen. We need to take our time. We need to be able to manage expectations as well as create them, we need to be agreed in our understanding of what we need to be doing and we need to value consumers and engage at an authentic level rather than a tokenistic level and that again is not always easy. I just wanted to move on now to talk about different language, the language of coproduction, cocreation and codesign. I've heard codesign used a few times today. I'm not sure I've heard the other two, but it's for me quite an interesting... I'm a researcher, I find all sorts of useless things interesting, but I think it's quite interesting to look at some of this and along with that, if you just remember back to the beginning of the presentation where I was talking about the three different traditions that, or the philosophies that we work from, we translate those philosophies also into the language that we're using when we're working with people and this is not necessarily about research. This literature that I'm drawing on for here is more generally in health services and coproduction usually is associated with an activity that's surrounding the delivery of health care. So how do I deliver this particular care in this particular instance? What we're doing is producing something together, we're doing it between the health services and the consumers. Codesign usually relates to the design of a service delivery process and it includes technology, so when we're talking about selfmanagement for example, it often includes things like developing phone apps that consumers might use and what makes them userfriendly. So codesign is often used from that perspective. Cocreation is a word that I haven't heard terribly often and it's probably the most interesting component of consumer engagement for me. The literature talks about the cocreation of value and to me previously as a clinician and currently as a researcher, it's in the interaction that I have with another person in which value is created. So for people who have a poor experience of health services, what they've had is something where either they haven't felt valued or the value that's been created or not created in that interaction is less than what they would have done. Where the words coproduction and codesign are about the processes that we use and how we make them better, to get to the heart of the experience and to make things truly different when we're moving forward means that you and I together need to work on something that's valuable to all of us. It needs to be valuable in many ways for the health service, because the health services are often coming from that perspective of effectiveness, quality, safety, those kinds of things. Sometimes with the nothing about me without me kind of approach that's going with that, but it's in the interaction that we have that value's created. It's also in the interaction that we have that value can be destroyed and so it's really important that we understand what happens in that context. The argument for coproduction then is that it facilitates empowerment. That's definitely the nothing about me without me, it's underpinned by theoretical understandings of self-determination, autonomy, I have a right to decide what I need to do. It acknowledges and combines the work and experience of each individual. It blurs the boundaries between scientists, service providers and service users and when it's used effectively some of the literature talks about it effectively puts termites in ivory towers. It adds diversity to the traditional ways of thinking and I think that's absolutely essential. Cocreation... and that's what I was talking, it engages in the values-guided action. It's very much more about what's important to me, what's important to you. Its aim is to change the service environment and the way that consumers are perceived or thought about and I certainly heard that in the last presentation, as well. It requires commitment, effective communication practices and values the humanity and perspective of each contributor in the collaboration process. So we're all equally important in that process. And codesign as I said, aims to improve the health of people in the community by involving them in the creation of tangible outputs. It uses a participatory process, but it's often around the design of care spaces. The design of buildings, care pathways or however you want to frame that language, and also about those technological interventions that happen. So my takehome message about language of coproduction and codesign, cocreation involving consumers in research is it really is all about perspective. Sometimes we need some glasses on and some of us are looking at forests and some of us are looking at cities and it's really quite different in how we go about doing that. So I'm going to hand over to Faiza Elhigzi. Now that you've got the boring theoretical component of what we've talked about, I'm sure Faiza is going to be more interesting and tell you of her experience with the QEII Hospital.

APPLAUSE

FAIZA ELHIGZI: I'm not going to stand up there, I'm going to come closer to you, because I can sense that you're very tired and I'm the last thing standing between you and freedom, so I will make this as less painful as possible. My name is Faiza and I am in the consumer advisory council of the QE II Hospital in Brisbane which is part of the Metro south region. Does that sound important? Absolutely, I feel important... that's okay. Look, can I just get you if you can stand up and shake it like that, because you've been sitting for two hours. So very quickly I'm going to talk about three things. I'm going to talk about my experience at the Consumer Council and then I'm going to talk about a couple of examples that... cocreation, and then I'll talk about the skills required for the consumer council. So the council I sit on is at a facility level, so it's a council for a hospital, an advisory council for a hospital, but it also links with the Metro south at the network level. So we do meet at the network level at Metro south which is a very large area. It's the most multicultural area in Queensland. For those of us who are on facilities or consumer networks, how ethically diverse are your consumer councils? So that's another thing, we are a nation that's ethically diverse and the funny thing is we started 20 years ago being called ethically diverse, then we became nonEnglish speaking, then we became CA LD, we turned CA LD culturally or linguistically diverse and now all of a sudden now we're English as a against language, so even the terminologies are changing. But I think there are almost like 50 nationalities if not more in Queensland, and the southeast has the most diversity and when we're talking about diversity, the important thing is to realise it's not all about language, because there are second generation, third generation people of different ethnic groups who've been born here. People by all means are Australians, they think like Australians, they are Australians. So they might look different, but they are part of the community, so their needs in terms of health are just like everybody's needs. Then there are the migrants, the migrants are people who came here based on their skill level, or based on their business acumen, so they have capacity to engage with the system. And then there are the emerging communities who came here as refugees and these are the groups that need the most assistance, because they might not have the language, they might not have the skills to communicate, and they might not have the capacity to advocate for themselves and I think with many migrants who come from developing or semi-democratic countries, their understanding of health care is coming from a low base. Even when they're engaged in consumer advisory councils, their contribution tends to be at an experience level rather than at a facility development level and it's important to understand as Carolyn has been saying that the engagements require from us different sets of skills. So, for example, the QE II Hospital where we meet quite regularly for one hour every month, we have set agenda. We come, it's a very professional meeting. We sit around a table with an executive director. We have representatives from every department in the hospital. We have a surgeon there, the other day he was sitting next to me in his surgery robes and even the stuff that they wear on their shoe. He shuffled out of the surgery and came to sit next to us in the meeting. We have a nurse representative and in my previous life I used to be an economist, so I look around me, I look at the table where there are eight professionals and then I calculate that for this hour, it's costing the service probably $35,000. For me, that's a responsibility. I feel I have a responsibility to contribute and to contribute something good during that hour, but then again how do you contribute? How do you understand? Am I talking about my own experience? Am I an advocate for my people? Who are my people? Like, I'm a Muslim, I'm a woman, I'm black... so who am I talking about here? So all these issues when you're sitting as a consumer, people are looking at you, what are they expecting of you on the other side of the table? These are all issues that we don't talk about, but we expect that the consumer would fall into something and they would tell us something about it. So one of the examples of the cocreation things that we participated in is nutrition at the QE II Hospital because again for ethnic people waking up in the morning and having cereal for breakfast is not cool, definitely not cool, especially when you're not feeling well. Cold milk and crunchy stuff doesn't work for us. We need something spicy, something that brings life into you again, so we started talking about food and as part of that we've changed the menu. There is kosher, Halal all sorts of things, it's not just vegan and vegetarian and coaliac, it's other things, as well. For me that was an interesting process, because that also links us to the facility itself and issues like budgets, issues like processes within the facility and so on. We also had a number of sessions where we provided information about end of life in the different cultures. We had Chinese, we had Indians, Buddhists and so on. What does end of life mean? All of us are going to end up in hospital and die at some point in time, so how is that process managed in a way that gives closure to the families? That information has been collated and is now part of a module that is a training module for the staff there. So these are all the things that we have worked with the hospital on and the third point about the skills that are required. So sitting at a table where that hour is costing the facility or the government around $5,000, what sort of a skill is required from me as a consumer? As I said, we get sent reports, minutes, surveys, and some of you probably saw some of the fantastic diagrams and we get sent these things and are asked to comment on them and that requires skills to understand what it is and to understand what is meant when you say leadership, or when we say consumer engagement, or when we say whatever it is that we say. These are skills that we don't talk about when we're talking about consumer training. Consumer training can mean a lot of things, but where do you want the consumers to hit? Within the QE II Hospital we engage in quality improvement, so plant trees has been rolled out, we've been involved in that process. Quality involvement, workplace health and safety, redesigning of the place, so it's a variety of things that consumers are now expected to participate in. In the olden days when consumers were not there, the facilities used to pay big dollars to get consultants to come in and tell them what is going to happen and they didn't usually get it, but now they get consumers for free, so you really need to respect us people. These are some of the issues that we as consumers are faced with, the responsibility of how do we participate? How do we frame the issues so they are picked up? Within the multicultural community, many of us come from an advocacy and social justice space and so sometimes you get emotionally involved in the issues and sometimes you're sitting around the meeting and someone is getting engaged and digging in and wanting a result. Consumer engagement is a process, it's a journey, it's not a destination and things happen slowly because you are not only engaging in cultural change, you're engaging in a process where things have to be approved. There have to be budgets for them, they have to go through certain processes, abide by certain things and so on. So it requires even that level of understanding of how the system operates for it to happen, and I'll leave it there. Thank you very much for your attention. (APPLAUSE).

NEW SPEAKER: Another very informative presentation. It's encouraging to know that there are some hospital health services that have reasonable engagement models and this is a great forum to share those models, so I hope there's a few takehome messages from your presentation and certainly the research perspective, most interesting to have that perspective and we look forward at HCQ to the results of your indepth research of our organisation, as well. Are there questions at all? Surely, there must be at least one question.

NEW SPEAKER: It's the comment about getting the spicy food put into the hospital and having been an inpatient of the Royal Brisbane for 25 days and complaining nonstop about the food and nobody except elderly white Australians would like the food, that please how do we get it implemented at other hospitals, too?

NEW SPEAKER: Excellent question, I'm of the same opinion, the food is atrocious. Any clues?

FAIZA ELHIGZI: You raise an important point. Everybody who came and presented had some innovative ideas that have been implemented at a facility level or at the regional level. How can we bring all these ideas to a central point so that they can be shared, you know, at this system level within Queensland Health? Whether it's food, or whether it's consumers sitting in selection committees for hiring executives or whatever it is and I think that's something that perhaps consumer Queensland, consumer engagement Queensland could take as a takehome message and become a conduit. I don't know, but it is a very important point.

NEW SPEAKER: Certainly after the conference we will be doing a debrief and perhaps if you have suggestions of changes required, when you complete the survey document, you can just add those comments, but certainly we have been taking notes and certainly there have been some interesting innovations and suggestions and we'll be discussing them at our board and that'll be passed on to Queensland Health and other service providers. Any other questions at all?

NEW SPEAKER: I would just like... if you have any ideas on how we can connect with different cultural groups? We have tried to find different culturally and linguistically diverse people to join our group. We would like a lot more diversity, we want it, but we can't seem to find them and the ones we speak to don't want to join us. How are we going to find the people that want to take part?

FAIZA ELHIGZI: That's a great question, thank you very much. It's not easy, because as I said nonEnglish speaking people or culturally diverse people, the few of us who are out and about are in everything, because people know you and then they come and ask you and we do a lot of volunteer things. I'm on so many boards and things that sometimes I forget, I just wake up in the morning, I've got a meeting, I don't even know what meeting it is. Again, like our people don't apply, so when you put something out... and I send stuff to people, they don't apply. It has to be word of mouth and it has to be recommendation so you probably need to link, and I can talk to you, whether it's the Ethnic Communities Council or MDA or African Council or Islamic Association, you need to have these connections and these people generally come to conferences and so on. Connect with them and then when you need someone you pick up the phone. I need someone by this date and then they will get the someone for you.

NEW SPEAKER: Just to add to that, may I suggest that you make contact with Health Consumers Queensland who have twice weekly email distribution of available positions and I'm sure they'd be happy to list any request to have special interest input. Any other questions? I know you're all desperate to leave, but we have a summary session that will commence in about 5 minutes or so. Is that correct, Jo?

NEW SPEAKER: I didn't know that.

NEW SPEAKER: According to my program, there's supposedly a summary, but just in case there is not, I'll take the opportunity to thank you all for your participation and we're really pleased that we had such a wonderful turnup here in Townsville. We really thought that we wouldn't make the numbers that we made in Brisbane. We would really appreciate your feedback. We know there have been technical problems today associated with the venue and we apologise for that inconvenience, but I sincerely thank you for your passionate and strong input and I would urge you to maintain that strength and compassion and ensure that consumers do have meaningful input into the health system. Thank you again for your input.

APPLAUSE

I've been reminded, the evaluation form is a must. Can't get outside the door, we won't let you go until you've completed that form. If you can't do it today, pop it in the post, but we would appreciate it, because it's instrumental in us framing our next conference whenever that might be, so thank you again. Thank you everyone, see you next year.