Day 2 – Concurrent Session 2

Facilitated by Jo Smethurst, Health Consumers Queensland

The Evolution of Consumer Advisory Committees

Central Queensland Hospital and Health Service

- **Steve Williamson, Chief Executive**
- **Raelene Ensby, Consumer Representative**

Darling Downs Hospital and Health Service

- **Donna Lucas, Consumer and Community Engagement Officer**
- **Jim Madden, Consumer Council Representative**
- **Russell Bridge, Toowoomba Hospital Consumer Advisory Group Representative and Chair**

Torres and Cape Hospital and Health Service

- **Dr Sean Taylor, Principal Advisor, Aboriginal and Torres Strait Islander Health**
- **Robert Tamwoy, Consumer Representative**
- **William Luthi, Consumer Representative**

Jo Smethurst: Now we've just got a bit under 30 minutes for questions. I know I've got a zillion in my head, but this is your chance to ask questions. We've got two roving mics, so if you'd like to ask a question put your hand up and if it's specific to a particular HHS or person, perhaps let them know you're asking the question to them. If it's a question that you'd like many people on the panel to answer, then maybe let us know that as well. Who wants to go first? Helen, birthday girl down the front here. Can you put your hand up please? Should we sing happy birthday to Helen while we wait? I'm not going to lead it.

(All sing Happy Birthday)

Audience member: Thank you! I've forgotten my question now. It's for the Torres Strait Islander mob. With your yes survey, why do you think that there wasn't an uptake of it? What's the survey about and what do you think the barriers were?

TCHHS member: Okay, absolutely. So the yes survey covers a whole range of issues, but what it basically is, is it's a survey to acquire what are the people that are using services? Are they actually being listened to, are they being heard? It's about are they actually happy with the services that are being provided to them or do they think there's room for improvement? The survey is like three or four pages, quite a long survey and it does cover a wide variety of issues, but basically it's about whether or not consumers are happy with the services that they're getting and if things need to be changed? Why it didn't work, it could be maybe the delivery of the survey wasn't widespread enough. Maybe it just wasn't organised enough so that consumers could come in and fill them out. I would also tend to think that consumers possibly even though services may not be suited or they're not happy they don't want to express those views for whatever reasons.

Audience member: Is it possible it's the name of the survey? Because there's a preconception like when you said "the yes survey" I was thinking is that your preferred outcome, that people are going to say yes they're really happy? Could it have been a psychological barrier?

TCHHS member: This came up in our meeting in Cooktown a couple of months ago and it was brought that when we heard the yes survey it automatically went to the equality, the marriage equality. So we were assuming that at the same time it was administered in the region it was also when the yes vote was going. So we think it could have been people didn't understand the survey versus the vote. So that could have been another possibility.

Jo Smethurst: Great. Another question? There's one down here at the front. Oh, there's one at the back. We'll go to the back and then the front.

Audience member: My name is Muriel and I was curious what Central Queensland is doing to help the Indigenous people with their diabetes and being obese and smoking and just what sort of are you doing to educate them? So someone from Central Queensland please.

Steve Williamson: I'll start to answer that and then Raelene might want to add to that, as well. So we've recognised in Central Queensland all the things I talked to you about, that high smoking rate, that high Type 2 Diabetes, the high levels of alcohol drinking at a risk level. All of those are significant risk factors for Indigenous communities in Central Queensland. Whilst the Central Queensland smoking rate as an example is 17 per cent, we know for some Indigenous communities or parts of those communities it might be 50 or 60 per cent, so huge challenges. We are trying to address that as best we can, so in areas like Woorabinda, we have formed health and well-being partnership in Woorabinda with Elders, the council, the hospital and health services there, the primary health network and the partners in Woorabinda to try to have much more tailored, much more targeted, much more focused support that is delivered in a way that meets the needs and expectations of that community. So all of the things that we do at an HHS level like our 10,000 lives smoking program we are trying to tailor so it is delivered in a way that best meets the needs of Indigenous communities in Central Queensland.

In the Woorabinda example we started to make significant progress within that, but of course that's only one community across 115,000 square kilometres. We're working now about what that looks like for Aboriginal and Torres Strait Islander communities in terms of that smoking intervention, that smoking support and for obesity and for Type 2 Diabetes that falls out of that, as well. We recognise in our consumer and consumer engagement, the challenges we have as a service in finding the right ways to engage and support and interact and change how we deliver our services to Indigenous peoples across Central Queensland.

So we're at the start of a journey. Our board have made some investment decisions very recently to do things like strengthen the leadership that we have within our hospital and health service to reflect the needs of Aboriginal and Torres Strait Islander people in

Central Queensland and I think that is leading us now to investment in director roles and organisation and infrastructure to help drive that forward. We've unashamedly tried to learn from good practice in other hospital and health services that have that greater level of engagement or that greater level of resource or greater level of leadership, or their whole structure. So we're on a journey here where we're trying to drive those things forward and where we have successes with particular communities we then try and take that approach and roll it out right across the rest of Central Queensland hospital and health service and we're also working hard with our staff across the whole of the hospital and health service.

Every single service we provide is provided for Aboriginal and Torres Strait Islander people, so having that approach in our organisation, that Indigenous health is everyone's business is something that we're really driving forward. We'd be very happy to share some of the specific things we're doing on the smoking cessation program specifically where we're probably further advanced, but we've also done a lot of work around breast screening and what we can do in those areas in a very strong program in Central Queensland, as well.

Audience member: The statistics are quite frightening, aren't they?

Steve Williamson: They are a huge challenge for us and I was really very, very positively... not surprised, but really pleased with the commitment that our board showed in setting our long-term strategy a target that you can measure us on in terms of eliminating that 12-year life expectancy gap. We've put milestones in for 2020 and 2025 and we're starting to develop year by year milestones that will show the progress we make and we've got some really good examples where we're implementing diabetes programs that you can measure us against so we can be held to account by the community in terms of the steps that we're taking. We had some very strong engagement from our consumer and community advisory committee to say that strategy is fantastic, but needs to be brought to life in ways we can measure, we can be transparent, absolutely clear where we're making progress and also be absolutely clear where we're having challenges. That's

been really helpful to see that, as well.

Audience member: Well congratulations, it's really nice to see you're not disenchanted with it all, because it's a huge project. Well done.

Jo Smethurst: Great, thank you. So we'll take a question here with Kathy and then there's a lady at the back and then we might bring the microphone forward to Louise and then I think at the front and there's another lady there.

Audience member: Hello, I'm Kathy, I'm a consumer. You've all got quite major challenges with geography and distance and I think you've all mentioned telehealth, so I'd like to know what reaction and what responses you have from consumers and communities around telehealth services and how that fits with the HHS's priorities?

Panel member: About telehealth? I think it's divided. Some people think it's really good, it's very useful, because you don't have to travel long distances to attend meetings. Others think it's not so good because of the quality of interaction, because you're not face-to-face with other people. It's actually over a computer screen. In some ways it is really good, because people can engage without having to travel long distances. But in other ways obviously it's not so good.

Jo Smethurst: Did someone else on the panel want to respond to that, as well?

Dr Sean Taylor: We had a parliamentary inquiry into telehealth and the Torres sort of led that looking at asking all our consumers around what they felt about telehealth. We had the DG was there and we had different consumers and each consumer on the different islands spoke about their experience and everybody was in agreeance to telehealth and their acceptance of telehealth, because we're geographically challenged in our region. We don't have roads, it's all islands so telehealth is quite important for us and because of the costs of travel for patients to travel, somebody needs to travel from Murray Island to Horn Island and to Kearns that's nearly $1200. We've got how many patients with chronic disease that has to come to Cairns, that's an enormous amount so telehealth is a useful

mode of service delivery for us.

>>: Sure.

Steve Williamson: I might just grab this microphone rather than standing up as well. We've had some feedback in Central Queensland to say one of the reasons people don't access health care or delay accessing health care is exactly the sorts of geographical challenges that have just been talked about. I'm conscious our region doesn't have the scale of the challenge that Torres and Cape has, but we have significant challenges and so we're starting to see feedback from consumers from communities from patients that is very positive in terms of telehealth where that service can be delivered really effectively. So that helps people access that care. What we've seen is we've had challenges within our organisation to encourage staff to think that telehealth is an effective way forward.

Even within organisations let alone within the communities, there is still work for all of us to do to share the success that telehealth can be, but also to share the challenges that come with that. I was in one of our smaller hospitals Blackwater a couple of weeks ago and they were telling me the difficulties of trying to run a small centre when we're still kind of imposing a large-scale approach on that where a telehealth for an orthopaedic appointment might be one day, but for a cardiac appointment that might be a different day and for a small opportunity that's difficult to manage. We see opportunities if we can implement digital medical records to turn that on its head and organise telehealth around the communities in blackwater rather than around the needs of different services. We've got a long way to go. I'm not celebrated we've completed that, but it's got us turning things on its head about how we organise things. We've worked very hard with Children's Health Queensland as the State specialist paediatric and children's provider and at the Royal Brisbane and Women's Hospital is an important tertiary provider for us so we can build confidence in our services and together deliver telehealth services rather than those telehealth service being provided by one hospital and health service. There's a really challenge for Queensland Health in thinking how do you organise that in the best interests of an individual resident or patient or consumer in Blackwater or Woorabinda or Gladstone or the gem fields rather than how we might traditionally organise ourselves, which is how

do we have the most productive outpatient organisation? Both things can be achieved, but they do take some time to get there.

Panel member: I think the telehealth area is a most important area in its development for consumers. It's one of these new pathways to health services and consumers and carers of consumers on the receiving end are in a position to note what are the difficulties and the problems with the technology for a start and secondly, with the way the services are presented from the health providers. In the development of telehealth, consumers have a have important role to play.

Jo Smethurst: Great, thank you panel.

Audience member: Hi, I'm Carrie, I work in the Darling Downs district and this is something that's really working at an isolated area is that we're working with all the GPs and the GPs are actually getting Skype, different things into their services which is also linking with us so that the consumers can get their own private selection as well as psychology and things like that. We also in the nursing homes, telehealth has got a wonderful set of fact sheets where you can get on to your iPad, on to your Anna log and phones so people that travel out to the mines we can link with them via their phones. We're breaking down, because we have a lot of those restrictions simply by greater community input, local nursing homes and things like that not just in the local hospitals.

Jo Smethurst: Great, thank you. We've got 10 minutes left for questions. Those people with questions, who's got a burning question about how the consumer advisory group works, some of the mechanics around consumer advisory groups?

Audience member: Thanks. My name is Danijela. I'm a consumer for the Sunshine Coast and I've been working with scientists on dementia research for the last eight years. We are told that just like diabetes, dementia is in much bigger numbers among the Aboriginal communities. So I would like to know from the consumers and everybody else, are there any programs for raising awareness about the illness or are you getting any help

from Dementia Australia to start working on these programs?

Jo Smethurst: I might throw Donna in this. I know that Texas is a dementia-friendly town and that's really been led by a consumer involved with the Darling Downs hospital and health service who's also a local government councillor. Is that right?

Donna Lucas: Yes, Texas has the label of a dementia-friendly town and they've been operating under that umbrella for a couple of years now to the point now where Inglewood and others are joining forces and actually undertaking that, if you want to call it at an accreditation as a dementia-friendly town. So they're doing different initiatives to try to build awareness within their community of some of those barriers with family members and just general knowledge within the community.

Jo Smethurst: Does anyone else on the panel want to talk about dementia at all? Go to another question. Great, thank you.

Audience member: I'm from Wellington Free Ambulance, all the way from New Zealand. I've been very impressed by the last two days. You guys are incredibly lucky to have consumers as health providers the national standards. At Wellington Free Ambulance we've just started our consumer development. So for both the consumers and the executives at the board at the table, you've mentioned the staff anxious, defensive, guarded, stubborn. You've mentioned that you've provided Senates. Do you have any other tips and advice for how to get the ball rolling so that staff are engaged?

Jim Madden: I'm sorry, I'm having difficulty hearing you, but I think you are asking me if I had any other ideas about promoting staff and consumer interaction. Am I correct?

Audience member: That's correct, even the council itself getting staff on board with the idea.

Jim Madden: Honestly, I think that the most important thing is that staff and consumers have to start by building a relationship with one another and they do that by

talking to one another. I know the situation in Toowoomba is that we have our meetings. The staff come along, 2 minutes, 1 minute before 10 o'clock, if the meeting begins at 10 and by one minute past 12 after the meeting finishes at 12 o'clock, they're all gone. What I did was I made arrangements whereby all the members of staff one by one, I'd make an appointment with them either before or after the meeting on the day I went to the hospital just to talk to them about what they did, what their department did, where they fit in in the hospital on the excuse that I feel I would be more effective if I knew them better and I knew what they were doing better. I'm just amazed at how remarkably well that has worked. I see them around the hospital. They'll pull up for a bit of a yarn about anything at all and now and then different ones come to me and say "Have you got any ideas about this, that or the other thing? " I think that basically try to get yourself or play yourself into the hospital by getting to know the people you're working with and take it from there.

Audience member: Great.

Jim Madden: Does that answer the question?

Audience member: That's great, thank you.

Jo Smethurst: Raelene is keen to respond and then we might have time for another quick question before we break.

Raelene Ensby: I guess the biggest thing I would say is we're governed by a terms of reference. That's revolving. So the consumers and the executive team are actually all on the same page for the first step and trust and respect comes. It's not always something - it's got to be earnt, as well. But I think the biggest thing is all being there for the same reason and having that term of reference you know you can change and it has to keep revolving. That's probably the first step.

Jo Smethurst: Great, thanks.

Audience member: Hi, my name is Kate, I'm from the health care Consumers' Association in Canberra. So my question is for the consumer members on the panel. It's about how you gather the consumer perspectives in a more broad way. What formal or informal ways do you have of hearing from your communities that perhaps have distance and language and culture barriers to giving feedback to health services? How do you achieve collecting those views? In the ACT we don't have so much of that distance and we have some culture barriers, but not the same ones, so I'd be interested in hearing about that?

Jo Smethurst: Because this is the final one I'd love to hear from Central Queensland, Darling Downs and Torres and Cape and one consumer from each. So if we start with Raelene please.

Raelene Ensby: So I would say when you're being a consumer for the group they're going to go on to sometimes you have to be a little bit selective and those networks that they have outside their own side of things is probably really important. Building the networks that they have outside. One thing we did as well is everybody got a business card. Not only did we feel important, but the community felt we had an importance. Just being able to hand out a business card that somebody can get in touch with you makes a big difference and it gave us that sense of, we're part of a team, we're proud to be doing what we're doing. So I think being selective of who your consumers are for what group is really important.

Jo Smethurst: Great, thanks Raelene. Russell, would you like to have a chance to say something?

Russell Bridge: I think I understand what your question is, if I haven't, just stop me please. I think you need to be a little bit careful as to who you have on your consumer advisory group - is that the question that you're asking?

Audience member: It was about how do you collect a broad perspective from different people in your communities. So you're the consumer representative, but how do

you know that you're getting a range of views from people given the distance and the cultural barriers that you have?

Jo Smethurst: Can you hear that, Russell? Did you hear? So it's about how do you make sure you're not just speaking from your own experience, but also that the experience that you're talking about is shared with consumers across the board? How do you use your informal and formal networks to be able to truly represent other consumers?

Russell Bridge: I'm a Guiding Star at the Toowoomba Hospital, so there's a massive range of different types of people coming through the hospital. If you listen closely to a lot of people and what their needs are and the hospital can provide those needs there and then, but there are some needs that just don't exist or they can be refined or made better. Getting back to the consumer advisory group and I'm just going to lead on from what Jim was saying and I hope I've answered your question there as best I can.

As I mentioned earlier, our consumer advisory group is really working internally at the present moment so we'll just focus on the internal one. There are consumer advisory members who come to the meetings and they say "Listen, I was talking to somebody from oncology or mental health or whenever it was and they were wondering if we could implement something to make life easier for visitors to those areas and also for some of the patients? " Lead on from that is that we will invite them to come to speak to us so we know what the exact need is and from there we can work on it and hopefully at the end of the day we'll get an outcome. Have I answered your question there? I've sort of diverted off a little bit, but it's really knowing what the need is in the hospital itself, what the staff need is, what the patient need is and what the family need is. We strive to try and achieve an outcome that is good for everyone and it's hard sometimes to do, but you've just got to work hard at it and you've got to network, you've got to liaise with people who can go to the next level, who can talk to the Toowoomba Hospital board, who can talk to the CEO and then get feedback to our group and say "this is achievable" and "no, it's not". And it's achievable because, and it's not achievable because.

Jo Smethurst: We're right on time. I'd love to hear from Robbie from Torres and Cape. Keep it short and sharp.

Robert Tamwoy: For me, engagement with the community. I'm really engaged, I work in the court system, in the local Magistrates Court and I work with the most vulnerable, so I work with the elders, I work with churches and listening from, not listening from your own consumer perspective, but from others. I'm a young person, I'm not sick so I don't know what a sick person is experiencing, so it's about listening what he or she is going for and how long the waiting hours is at the hospital. I'm not expecting to wait for an hour and that's what happens in our hospital, because we only have three doctors in our hospital. We're a population of 2,500 people, but it's about engagement. You have to engage with the community. We have five communities so I try to engage with everybody. 95 per cent of the community is Indigenous and they don't speak English, so I have to engage in that perspective. In coming not from a personal thing, but looking at somebody else, like we did yesterday the disabled workshop. It was very touching in the wheelchair doing the things and it's about living through other people's eyes too so you know first-hand what they're experiencing and you can speak from experience. So engagement. Got to engage, yeah.

Jo Smethurst: Thanks, Robbie. (APPLAUSE) I think that what this session has shown us is that the hospital and health services are using the consumer advisory groups and each of them are doing it differently, tailoring it for the needs of the community and that there is no one way of doing it, but it's about listening to the community and trying to get it right. Could we thank all of our panelists here today. (APPLAUSE) Thank you very much. It's been great and it's been my privilege to be able to travel to these areas and meet these people and support them in their work and I think I actually suggested to all three parties to put in an abstract to the forum, so I'm pleased to be facilitating this particular session.