Health Consumers Queensland Annual Forum 2018

### **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: Okay, so welcome to the session everyone. This session is going to well, I think it's going to be pretty awesome. We'll be show casing three different consumer advisory groups across three different hospital and health services here in Queensland. Each of them is doing fantastic work and each of them is doing it a little bit differently. So I think it's nice to see all the different ways that you can really meaningfully engage and partner with consumers. So on stage, let me just check, I know everyone, but I want to check I've got everyone's names right. Closest to me is Central Queensland Hospital and Health Service, we have Raelene Ensby, a consumer rep on the advisory group. Along with Steve Williamson the chief executive of the Central Queensland Hospital and Health



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Service. Welcome Raelene and Steven. The next three chairs are filled with beautiful people from the Darling Downs. We've got Donna Lucas who is the consumer engagement officer for Darling Downs. Along with her is Russell Bridge on the Toowoomba Hospital consumer advisory group, he's a representative and the chairperson of that group and sitting beside Russell is Jim Madden. Jim is a consumer council representative, so welcome Darling Downs. (APPLAUSE) Darling Downs have brought their fan club! We might have a little cheering off at the end of the session, so raise those voices and the final three seats belong to three beautiful people from the Torres and Cape Hospital and Health service. Dr Sean Taylor, he's the principal adviser of Aboriginal and Torres Strait Islander, and we have Robert Tamwoy and William Luthi. They've got a special story to share with you in the final session. So what we're going to do is hear from each of those three groups. They'll have 20 minutes each. We're going to save questions until right at the end so then we can have a lovely panel Q&A session for the final 30 minutes of this session. Without any further ado, I would like to welcome Raelene and Steven on stage. I'll give you a 10-minute wrap-up and 5 minutes and 1 minute so you know how long you've got and we keep to time. Thanks, everyone. (APPLAUSE)

Raelene Ensby: Bring it down for the short people. I would like to firstly acknowledge the traditional owners of the country today. The Central Queensland consumer and community advisory council would like to acknowledge the traditional owners of the country on which we work and live and recognise their continuing recollection to the land, waters and community. We pay our respect to them and cultures and to the Elders past present and emerging. I'd like to acknowledge Helen who I promised I would do this to her. It is her birthday today. For all those people in the room who have a birthday today, happy birthday, but thank you Helen. (APPLAUSE) I know payback will be coming, but that's okay. I guess what I'd like to talk about as a consumer is what we are doing in Rockhampton and around Central Queensland health and this presentation will outline some of the Central Queensland health services and we call our CCAK. We evolved since 2015. So in the past I guess what we talked about is a lot of, what we struggled with and those were overwhelming some of the barriers and challenges. The present we talk about partnerships and visions and the future is about the continual improvement and where we're going to go with that. When we think back to when it first



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started in 2015, it was I guess you probably also know it as seek your medical local, it's now known as PHN which everyone knows more. When we started these things this wasn't necessarily a thought of how do we improve the stuff and move forward with that. So let me introduce Steve to talk a little bit about who we are in Central Queensland and then I can explain to you what's happened in the past, the present and he will let you know what's happening in the future.

**Steve Williamson**: Great, thank you Raelene and it's a real privilege to talk to you as chief executive of Central Queensland hospital and health service. A little bit about who we are and where we are. I've been in Central Queensland for a year and a half now and it's a fantastic region. Beach to bush, great schools, great education, fantastic tourism, great industry, great business. Fantastic communities. Above all, a really great place to live, but we have our challenges like every other hospital and health service area and so I'll just share some of those challenges with you. Our population 235,000 is one of the fastest growing populations in regional and rural Queensland. We're expecting that population to grow by about 20 per cent, another 47 or 50,000 people living in Central Queensland by 2026 and our population is ageing, so whilst the overall population grows by about 20 per cent, the population of those over 65 forecast to grow by nearly 70 per cent. Our population has an amazing mix of different people. About 6 per cent of the Central Queensland population are Aboriginal and Torres Strait Islander people. Within our workforce we have about 3.5 per cent who are Aboriginal and Torres Strait Islander people. That's well ahead of the State average, but we've got some way to go to have a workforce which reflects our population in those terms. We've got high rates of smoking, higher than the Queensland State average. High rates of obesity, high rates of Type 2 Diabetes and high rates of drinking alcohol to risk levels and they all have a bearing, they have an impact, particularly those three - smoking obesity and alcohol consumption. They come together to mean that on average if you're a Central Queenslander you'll live two years less than the average across the whole of the State. That's for that entire population of 235,000. If you're an Aboriginal and Torres Strait Islander Central Queenslander then the life expectancy gap compared to the Queensland average of the whole population is much more significant. It's 12 years. There's real challenges that place demands on our communities, that place demands on our services and place demands on us as a hospital



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and health service provider. This is where we are. So we cover a large geographical area. I say I've been in Central Queensland for a year and a half. I came from the UK and I now know that England is the same size as Central Queensland 117,000 from Great Keppel and the Great Barrier Reef through Rockhampton, Gladstone, out to the gemfields.

We cover six council areas. I was in Woorabinda last week and I'll share one example. I know you'll have many more examples than I can have, but I was talking to one of our members of staff who needed to come for a vascular outpatient appointment in Brisbane. For her that was going to be a 3-day journey for a half an hour appointment. That's typical in Central Queensland, where the geography is a huge challenge and that geography plays a small part in the health challenges that we face and, of course, across a region and a geography like that we've got different communities with different challenges and different needs and we have to work very hard to understand those needs and respond appropriately. I'll say a little bit more about that when we get to the future, but I'm going to hand back to Raelene now.

Raelene Ensby: Thanks, Steve. It is quite a large area. It's not just 10 minutes to the shop everywhere we go. Some of the things I would like to talk to you about is our journey of how it aligns with the Health Consumers Queensland's principles and of the improvement which is underpinned by the health consumers principles partnership, inclusiveness, respect and dignity. We take the time to focus and reflect on how we are meeting our values. This is done at every meeting. One of those things we do is think about the care. Are we attendantive to the individual needs and circumstances at each meeting? The integrity. We are consistent, true, act diligent and lead by example. The respect, we will behave with courtesy, dignity and fairness and we will all do this. And the commitment, we will always do the best we can all of the time. These are probably some of the biggest things that we accept every time we have a meeting which is really about let's make sure everybody in the room is comfortable and everybody in the room wants to still be here.

So then we think about how we came from the past. Our partners developed as I said earlier from Medicare local now PHN and the forerunner of the CQ health CCAC was



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really over time it's become a group that I guess you could say went from not a lot of trust, not a lot of respect to thinking about what are the consequences of us having that group and why are we here to do that? The biggest thing that we can think about is our demographic footprint. That footprint is quite large as you've already seen. What were the barriers with regards to the dignity and developing the partnerships. The stubbornness. Sometimes when you're on a consumer group and I'm sure we've all been there, it can be a one-sided fence. It can also be about ticking the boxes and really whose boxes are those we're ticking? Humouring our consumers that's not okay, we don't want to do that. We want to have a purpose. I guess that's where our future went to from there. We thought about what wasn't working, so let's change what is now working. When we think about where we actually are today, wow, what a difference. My first words at the end of I guess the end of the past was, do I need to be here, is there a purpose? Now I'd be lost without them and they'd probably be lost without me, too. When we think about the present it's an evolving partnership. It's really about we now have a consumer as our chair. That was really important. It was run by Central Queensland health service, now our chair is the consumer who makes sure that meeting is run well and run for the purpose it's meant to be. We then think about the diverse culture and the geographic side of it. We want people with lived experience. It really makes a difference. We don't somebody who's just there, because they want to be.

Now we also think about the trust factor. The commitment from both sides where everybody's passionate. Everybody's involved. We're there because we have a purpose and a reason and an outcome. The venture became joint and driven by consumers which is really exciting to see where we've come from. The community of the Central Queensland health resulted in improvements and one of those things I'd really like to acknowledge is the standard 2. We met with merit which is an exciting achievement. Not only in one category, mental and sexual health along with Indigenous health. That's a big achievement from one of the things we've come from, we would have never thought that would happen in the past. I guess we're looking at the rest of the standards and making sure we do that again next time. Some of the barriers we still have are there. There will always be a barrier, but what we do with those barriers is I guess where we make that future a very big difference.



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So some of the things we think about is the lower management and general staff who attend meetings share information. Do they understand what consumers are? 10 minutes... gosh, I'd better slow down. So thinking about when we look at what we're doing now we're not just ticking the box. It's not a tick box for the consumers or for Central Queensland health. It's about ticking that box for everybody involved. We think about how does everybody in Central Queensland health work with consumers. We think about where does it align with our visions? We continue to build trust and create safe spaces and we also think about the shared space. Something that we always need to do is that shared space. The vision and logo was created this year which is also about strengthening the consumer voice in Queensland Health. As I said before sometimes the challenge can also be becoming too successful, which we've done. We now have a really full agenda. Every meeting we wonder if we're going to get through it, is there enough time in the day? The extensive reading becomes quite a lot. That's probably something we need to think about, how to reduce that side of it. Who's got time? Consumers often have other jobs and priorities as well.

So we think about those communication barriers as I said with the lower management and general staff. Sometimes appear anxious, defensive and guard. How do we bring that into that so they're understanding the consumers' side of things and also their own, and then the broader vision of the hospital. The impacts on open and frank discussions. There's quite a few of those and the passion comes out in people. We understand because of that trust we now have. It's not about "he said, she said" it's about how do we make a bigger difference? The collaboration and the innovation. We're all advocates for change, we all want something different and want to have that wonderful experience whenever we go. I guess the biggest part, we need to continue to build trust and creating a shared safe space so we can continue to have advocates, consumers and a hospital health board that really want us to be involved. In saying that when we think about the future and the past and even now the present, we think about how much it's changed, how much we've made that difference change, but it's been a partnership that's changed that and that's what I think is the most important thing we can get out of it. That partnership doesn't have a value, it's priceless. Let's think about the future and Steve is



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going to mention some of the things planned for the future and how we're going to continue this partnership.

**Steven Williamson:** Thanks, Raelene. One of the challenges for me as the chief executive has been how to build on that success that our consumer and community advisory committee and all of our consumer champions across Central Queensland have had and then move forward. I was very struck by Melissa's opening remarks this morning when she said the reason we're here is that we're united to improve the health outcome of Queenslanders. That really resonated with me and I think that's really important. We started some work in Central Queensland just over a year ago now developing a long-term strategic vision for the future of our region and our hospital and health service. That's a 12-year vision we call Destination 2030, great care for Central Queenslanders and that is all about working together in partnership in Central Queensland to improve the health outcomes of Central Queenslanders. I mentioned some of the challenges we face in Central Queensland with high smoking rates, high levels of obesity and Type 2 Diabetes and those other challenges, that 2-year life expectancy gap for all Central Queenslanders and that 12-year life expectancy gap for Indigenous Central Queenslanders.

Our vision for the futures is we eliminate that. By 2030 we don't have that 2-year life expectancy gap for all Central Queenslanders and we don't have that 12-year life expectancy gap for Indigenous Central Queenslanders and we recognise we can only possibly hope of achieving that if we have exceptional partnerships in Central Queensland. So that theme of partnerships runs right through everything we do. We recognise that if we don't change that smoking rate and just focus on that one issue, if that smoking rate doesn't change we will be nearly double the smoking rate of the best in the State as it stands right now and we'll have 10,000 more Central Queenslanders dead from smoking-related disease than should be the case if we were just at the level of the best in the State now. So we launched a program 10,000 Lives program in November last year to try and get people thinking about smoking cessation, about not taking it up. Since then, it's very early days, but we've had 100 per cent take-up in people registering for and accessing Quitline nicotine replacement patches and counselling. I can't say to you that's going to translate into a lower smoking rate, but as a start it's a step in the right direction, that's



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really exciting for me. We want to have 10,000 fewer patient journeys every single year as we deliver more care close to home. We see the challenges that we have just within Central Queensland and we see the challenges - I gave you the Woorabinda example of somebody having to spend three days of their time to travel for one half an hour appointment.

There is so much more we can do in Woorabinda, in Gladstone, in Emerald Hospital in Biloeoa Hospital in Rockhampton Hospital, even in patient's homes to deliver more care close to home and we think that plays an important part in how we close that gap. When we developed that strategy we had significant engagement, consultation, involvement, direction, challenge, all of those things from our community and consumer advisory committee and that was really powerful. This week I was interviewing for our executive director medical services role one of the most important roles in our organisation in terms of strategic leadership, and on the panel with me was Jeff our consumer chair of the community and consumer advisory committee. That's not tokenistic. That's one example of what we try to embed right across our organisation and we recognise the challenges that Raelene talked about. How do we help our managers across the organisation? How do we help all of our staff understand the importance of that engagement? Because it's that, that will change the services that we deliver.

We established a CQ clinical Senate that brings together front-line organisations to shape what we do for the future. That has fantastic clinicians, but it also as part of that clinical centre representation from our consumer and advisory committee. Everything we do tries to embed and weave that engagement into our organisation and the work for us right now is how we encourage our staff to see that as positive engaging. It makes a difference. There's nothing wrong with having made a mistake. There's nothing wrong with having a service that can be improved as long as we're open and passionate about making those improvements. For me it's a fantastic opportunity to work in partnership with a community and consumer advisory committee. They work very closely with me and I can tell you here and now they've made a huge difference to our organisation and I see many, many opportunities to build on that going forward. I finish with that point that Melissa made this morning, that we are united to improve the health outcomes in



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Queensland and in our case in Central Queensland. That's the thing that binds us together and I think that puts us in a fantastic position and I'm certain that we as a hospital and health service are incredibly fortunate to have such strong passionate engaging community and consumer advocates and have fantastic staff that will step up to that challenge and drive that forward, too. Thank you. (APPLAUSE)

**Jo Smethurst:** Fantastic, Steve and Raelene. That was awesome, makes me want to move for Rocky, not just for the beaches and the bush but because of your exciting vision and bold steps forward and a true partnership. We've seen that true partnership just modelled here beautifully with the chief executive being introduced by the consumer rep. That's awesome, thank you. Could Darling Downs now please come up. (APPLAUSE)

**Donna Lucas:** Good afternoon, everyone. I'm from the Darling Downs hospital and health service and like Central Queensland, we're unique in that we've got 26 facilities across 21 communities. Firstly, I'd like to acknowledge the traditional owners of the land on which we meet and pay my respects to the Elders past, present and emerging. I also would like to thank Russell and Jim our consumer reps that have agreed to share their experience as consumer representatives within the Darling Downs hospital and health service. I was fortunate enough, I've been accompanied by eight staff and eight consumer representatives here at this forum. (APPLAUSE) Yes, thank you. Great representation and great coverage of our district. We've got 300,000 community members across our district and we cover 90,000 square kilometres so not quite as big as Central Queensland, but like I said we've got 26 facilities in 21 communities.

In saying that, we've got 12 community advisory groups and four Aboriginal and Torres Strait Islander community advisory groups and one consumer council. So we're not covering all of our community areas, but we're certainly working towards that as all health services. We are evolving and growing as we're progressing across this consumer engagement. We also have 12 hospital ancillaries and some of those actually function within some of the communities that we don't have consumer advisory groups and with those consumer advisory groups we have them labelled as either community advisory networks which are the ones that come from the original multipurpose health services and



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we've also got community advisory groups and the community consultative committees. We haven't asked each of the groups to change their name. It's up to them what they would like to be known as. Same with our terms of reference. We give them a structure to help them to function as a group, but we're flexible with how the terms within those terms of reference. It's just so that each group can grow and establish themselves within their community, because they know what's needed within their community. Most of our members are recruited by our directors of nursing and facility managers within those communities. As you can imagine, most of the consumer representatives and community representatives are on multiple community groups within their small communities.

Hence, we just leave it up to them to nominate or provide that information to those members and also, the staff within our hospital facilities. They may come across someone that they've treated or a family member that they nominate and we make that approach. So we don't actually go out actively through an expression of interest through the media or anything like that to recruit our members. Our membership across all our groups varies. Anything from 8 to 30 members and we leave that up to each of the groups also to dictate how many members they would like to have on each group. Each group might encompass community representatives, but also community organisations so that you get that broader connection within the community and make sure that you get involvement from those that are harder to reach, so at least you've got some point of contact with most of the community.

Probably 50 per cent of our groups are chaired by community representatives and the other 50 per cent are by our local directors of nursing, facility managers and with our groups they may meet monthly, bimonthly or quarterly. We've got one that meets quarterly and the other eight meet monthly and eight meet bimonthly. Most of the meetings run between 1-2 hours just depending on the availability of their members and what suits them and those meetings can vary anything from first thing in the morning whichever suits the facility right through until after hours. We also provide each of our groups with an agenda template so they've got a structure they can function off. We also incorporate like Central Queensland, our values within those agendas, so that we can also try and inspire people to come up with innovative ideas or initiatives that they would like to



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undertake. We certainly try not to reinvent the wheel either. We try and borrow other people's ideas and mould it to suit our needs. We also find some of our smaller communities actually join forces and undertake initiatives together, which works very well. I also try to share these ideas across the district by providing a monthly update to all our groups and just outlining how often the groups meet. Some of the initiatives that they might be undertaking. It's a work in progress as far as sharing those ideas. Not everyone wants to nominate or share their points of interest. But like partnering with our consumers, it's evolving and hopefully that will grow, as well. Without going on too much further, I'd like to invite Russell up to share his experience as our chair for our Toowoomba Hospital consumer advisory group. (APPLAUSE)

Russell Bridge: Good afternoon, everyone. The Toowoomba Hospital consumer advisory group commenced around some time in 2014. It was just put out there for interest and about 25 or so people turned up to the first meeting. And it's interesting to note then and now even though numbers have dropped off a bit now that half were paid half and the other half are volunteers. People drop off as things go on, because it's not their cup of tea and it just doesn't fit with whatever's happening. Can I just say that for start right from the front that I'm a volunteer, I'm not paid by Queensland Health or anything like that. Sometimes I make a joke about it and say well, salary needs to go up next year, but it's great just to be a volunteer, can I just make that clear. It's really great to give something back to the community and do something that's positive and worthwhile. I've had the community to be chair of the consumer group for probably the last three years and I was given that opportunity and encouraged to give it a go. The only way I can do my role is because of other people and we work together as a team. I have a good secretary. The folks who are on the committee to date, we're working as a team. No one is working on their own. It's a team effort and we can't achieve anything unless we've got a team effort.

I guess over the years since I've been there, one of the major things that we have achieved internally, I'm talking internally for the hospital and I'll be talking mostly about that, is that there was a need to have some sort of way of getting people from the main entrance and Toowoomba Hospital is a fairly big place, but not as big as some. From the



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main entrance to their appointments and where they needed to be on the hospital grounds and a golf buggy was purchased. Probably one of the best things that we've ever done, but like most things it was "Oh, do we need one?" All the pros and cons and we ended up with one and it's pretty good and people really appreciate that they can have access to the golf buggy and we have about 10 places where we drop people off and pick people up and it's just about making life easy for everyone. There is a Toowoomba Hospital website which is really helpful to a lot of people, because our area is fairly large as well and if you have someone coming in from out at Cunnamulla to Toowoomba that's going to be scary enough anyway without coming to the hospital. So if they can access what they need to be accessing at the hospital. Parking, where they need to be, all those sorts of things, it's going to help. And there's people in Toowoomba that will need that help as well, because it's not every day that you come to the hospital just for something to do. Getting back to our consumer advisory group, we in the last year or so we have really been working hard to improve a lot of things within the hospital itself for patients, families and staff.

It's not easy, but you've got to work at it and if there's a challenge there well, we just need to go about it in the way that we can. Use people who are willing to be on board to achieve an end goal and to have the Toowoomba Hospital the best that we possibly can. At the present moment with the consumer advisory group we're looking at children's play area at the hospital. We're looking at an area where there's going to be privacy for interviews, for folks who are looking at coming on to staff, counselling, if the police need to be talking to someone. That's an area we don't have as a private area. It's a public space at the moment and that's not good, it don't work that way. What else can we talk about? But there's lots of great people, and we've sort of weeded it down... that's not the right word, but those who are on the consumer advisory group now are great people. They're all gifted in some way and that includes everyone. It doesn't matter whether you're an executive or whether you have a role as Donna has, or whether you're a volunteer.

Everyone has a gift and if we can pool all our resources and say well, that's hard but it's achievable and we just keep working at it. And you network people that aren't on the committee to understand that this is what we're trying to achieve for a better outcome for



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our community. Can I just say, one of the things I would really like to see happen is that we have more community representatives on our community advisory group. That's a little bit like pulling teeth sometimes, because a lot of people are interested and not interested and don't want to know about it. But it's important that we involve the community and we have their input so we can improve the Toowoomba Hospital, what they provide, we can improve for our community. At the end of the day, it's really making sure - and I have a bad habit of stepping out of the circle, and I'll wear that - personally, if I see something that's worthwhile achieving for the Toowoomba Hospital to go ahead, it's worthwhile stepping out of the circle. Can I just finish off by saying we've got to work as a team, we do work as a team. We've got some really great people. If we get to a stage where we're going to get other people coming on so we continue to grow and build ourselves, we'll do it. Thank you. (APPLAUSE).

Jim Madden: Good afternoon, ladies and gentlemen. My name is Jim Madden and I'm a consumer representative at the Toowoomba Base Hospital and the other hospitals of the area. Just before I start, I want to congratulate the organisers on that wonderful Welcome to Country we had this morning. I've never been as impressed with a Welcome to Country as I was with that one, and the Aboriginal representative gave a marvellous and a warm welcome to us all and I only thought if the Aborigines at Botany Bay in 1788 could have given such a welcome and captain Phillip and his sailors and soldiers and his convicts could have responded as we did, our history might have been somewhat different.

Anyway, the other thing I just want to say is a lot of people have approached me and they've said, why have you got a green spot on your cards? I've said "Well, you know, you never know", but I think that Catholics at one time they used to carry these little things in their pockets it was called a piety kit and it had a little note inside it "I'm a Catholic in case of accident, call a priest", and that wasn't quite for all Catholics. There were Catholic bank managers and doctors and people in those higher echelons, they had a special one. And the card read "I am an important Catholic, in case of an accident, call a bishop", so I'm just going to leave it at that. Anyway, I've been a consumer representative of the Toowoomba Base Hospital for a bit over three years now and prior to this and the thread that runs through my life and gives it some unity is that I've always been an educator and as an



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educator I believe that I was there to promote better education outcomes for more people. I've been able very easily to transfer that to better health education, better health outcomes for more people. I'm not going to go into concrete details of what I've been doing, but rather give you a reflection on those in this evolution of consumer inclusion in our work in Toowoomba.

The first thing I'd like to say is in seeing consumers I feel that what we've been able to contribute is that we have a different perspective. We see things outside the box, like the hospital people, their scene of the action is inside the hospital walls. They get cocooned there and we come along and say "Hey, there's another way of doing this, there's another side to look at it", and that's what we can contribute and that helps us to make that contribution to better health outcomes. As well, we can see different ways of doing things. Alternative paths to health services, so I think they're the important roles for consumers. To see the different perspectives and the different pathways to health services. Of course, the consumers then interact with the health service providers and what I've found is that the health service providers are very good at responding well to anything I've had to say and to what other consumers have had to say. I've had a contact person for the three years I've been there, but I've had three contact people and each one has been very good in listening to what I say, but it doesn't end there.

After I've spoken to some of these, they've come back to me and said "Well, I was talking to the executive director, I was talking to the director of nursing in a certain area and they liked what you said and they're going to do something about it" or I've run into those people in the corridors around the hospital and they say, come in and talk about those things you said to Pauline or to Donna or to alley. So we do have our influence, and if our intentions are good and our perspective is good they're willing to listen. I think that there are some things that we can say at times. They might not be taken quite literally or carried through to what we suggest, but they start the beginning of it. Outside the hospital in Toowoomba there's a roadway and it's a very busy roadway and there's lights down at the intersection which is James Street and that's where all the big transport runs through Toowoomba on its way to Sydney and Melbourne.



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Anyway, I made a suggestion one day and they couldn't do much about it, but they have done something about it. I think this acceptance is really great and I feel very much at home at the Toowoomba General Hospital and the other places I've been associated with, with the general hospital. I think these are the principles or the foundations on which our community and consumer involvement has been based and is developing at the general hospital in Toowoomba in the Darling Downs health and hospital services area. I think by building on these principles - and others I'm sure will be added in time - that we are making progress. It may be slow at times, but we are making progress and as Jack Davey used to say... you wouldn't remember Jack Davey used to say, would you? But he used to say "Thanks very much for listening". (APPLAUSE)

**Jo Smethurst:** Thank you so much, Jim, Russell and Donna. That was fabulous. Now we've got Torres and Cape going to share their pearls of wisdom with us about their very new consumer advisory group.

Dr Sean Taylor: Thanks, Jo. Firstly I'd like to acknowledge the traditional owners on the land we're gathered here today, respect their Elders past, present and emerging. I'm Sean Taylor, the principal adviser for the Torres and Cape health service. It forms part of the executive committee and I'm also the founding chair for the consumer advisory the Torres and Cape advisory committee. Just a bit of background to our HHS. Our two consumers will talk about what consumers do in our meetings and William will talk about the mental health consumer group and he's also part of the larger group. So a bit of background about the Torres and Cape hospital and health service. It covers more than 130,000 square kilometres. It is responsible for the health service of 365,000 people, widely spread across the Cape York, northern peninsula area and the Torres Strait Islander Islands. The northern peninsula area is the most remote HHS in northern Queensland. We have more than 900 FTEs across the region, where the fourth smallest HHS in Queensland and we have 17 islands, inhabited islands with a primary health centre in the Torres Strait region and we border with Papua New Guinea. Our facilities, there are 31 primary health care centres, two hospitals. Thursday island and Bamaga.



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We have a multipod health service in Cooktown. You need to have a consumer advisory network committee and William sits on that committee, as well and an integrated health service in Weipa. Our significant capital works projects are under way with major health centres. We've got 36 million for redevelopment of the Thursday Island hospital. 23 million in upgrades in the outer islands primary health care centres. We've got 126K funded for the Cooktown master plan with a total estimate of \$82 million in capital works. So our consumers, the Torres and Cape is one of Australia's largest providers of health service to Aboriginal and Torres Strait Islander people, provides health care to a resident population of 25,000 which 63.7 identify as Aboriginal or Torres Strait Islander and it's adjacent to Papua New Guinea. During 2016-17 we delivered 221,000 health care occasions of service which included 4,026 visiting specialists, consultations and 1,332 telehealth consultations and there were 23,634 presentations.

The majority of the residents reside in the most disadvantaged bracket highlighting relative social disadvantage to the region and this reflected the health gap such as poor life expectancy and high levels of chronic disease and Torres Strait Islanders have the highest prevalence of Type 2 Diabetes in Australia, so we've got a lot of chronic disease that's coming through our health service. So the Torres and Cape hospital and health service consumer advisory group, falls under my portfolio. During my time as a researcher with James Cook University I spent six years working in the Torres and Cape working with patients and when I came on board as the principal adviser with standard 2 I tapped a lot of my patients on the shoulder and said "Hey, I wanted to develop a consumer advisory group, would you guys be interested in applying? "So I spoke to a number of people, but at the time I could only get four and this photo here is at the inaugural meeting we had at Cairns and the four that are sitting to your left are the four that were the first to sit on this committee and the rest were staff that was presented. They become staff of the Torres and Cape hospital and health service. I pay them sitting fees, I pay for air Farrs and travelling allowance to the different hubs. So we meet in Cooktown, Weipa, Thursday Island and Bam aga. The training is provided by health consumer Queensland and Jo has provided two trainings to our consumer groups. One in Cairns and one in Cooktown recently. A logo will be developed with the Torres and Cape hospital and health service. Any documents approved through this committee will have the logo stamped especially



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with pamphlets and any other documents. The Cairns and hinterland hospital and health service has requested our chair to sit on their committee and in our upcoming meeting in Weipa in two weeks' time I will hand over to the new chair that will be announced for this committee. So I'll just pass it over to Robbie and Robbie will discuss the consumer groups.

**Robert Tamwoy:** Good afternoon, everybody. How are you guys? You doing all right? Give me a wave if you're having a good conference. Turn to your neighbour and say "Keep going", turn to someone and say "Keep going, you're doing a good job". (Speaks Indigenous language) Hello everybody, my name is Robert Tamwoy, I'm from... my wind is the east wind. My totem is a stingray. I want to welcome everybody and say thank you to all the health consumer Queensland for getting us here, getting me here all the way from the top and just paying for everything. I want to thank Jo for the training she delivered and the organisers of this conference. You're doing a good job. The brother with the good hair there. (APPLAUSE) Just give him a round of applause. I tell the board members, thank them for their hard work again and thank my boss here brother Dr Sean Taylor. I'm part of the consumer group. I'm one of the members. I'm from a place called Umagico at the top of the continent. They call it the tip. It's not the dump, it's the tip. It's the tip of the continent of Australia. Anyone been? Good fishing, lots of crocodiles. We are one member from Murray Island. We have two members from Thursday Island. I forgot their names, actually. They are good names. We have Dallas from Weipa, I haven't met them there. We've got a brother over there Will from Cooktown and Aunty Lou an Indigenous elder part of our group from Cooktown and Wendy and myself from MPA. There's five Indigenous communities and I'm from one of them and we started the group in August, the brother started the group and we met three times so far. We meet quarterly and we meet all over the region and we do three days workshop as Jo has come up and been a part of.

We've been given brochures that the health system are going to put in the hospital, the health centres and we get given them first and then we review them. If they look right, they sound right and if we can understand that, because English is not our first language and I know a lot of us can't talk the big health words so we want to make it simple and understandable. We went through the end of life brochure application form and tweaked it a bit for our area and I think we changed the whole name I think. I'm not sure, because



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we're talking about end of life. If you're not living then you're not alive, so I'm not sure, but it's confusing me again. We got consumer brochures, English is not our first language. We've got too much language up there. Broken English, up there we've taken English and broken it in half thanks to Captain Cook. I've got 10 minutes left. Travel documents for patients, so we reviewed that. A lot of times patients were going to Cairns. One Elder went down and didn't know how to get to the hospital, or didn't know how to use the lift. We went to a TB lab and we influenced the research there. We went through a patient survey and we engaged with the post office. We were trying to find out how these mails travel to our communities and we found out that our mail, so if we sent it to Bam aga, it will have to go to Cairns first and it goes via ferry so it takes three days to get there and another three days to get back up. So appointment comes and no one shows up. Why didn't you show up? There's no mail in the post office. So the thing could be in the big ship there somewhere, so we gave ideas of using a drone too to deliver mail. That's one of the ideas that we can travel. But that's about it, we're trying to do our best there and I want to thank everybody again for listening. Keep going, keep fighting the fight all you consumers. God bless.

William Luthi: Hey, everyone. I'm Will, I'm from Cooktown. I'm a consumer representative for mental health and ATODS for the Torres and Cape. I'm new at all of this. I haven't been on a lot of committees. Having said that, I started off with an advisory group for the Torres and Cape hospital and health service for the meeting in Cooktown and we talked about a lot of different issues being remote and rural we have all sorts of problems. For instance, travel and logistics, things like that. People needing specialist appointments and having to travel long distances on dirt roads and stuff. It's a bit of a different sort of a life and a world up there in North Queensland. Things can happen a little bit slower. It's more difficult to have and reach services. A lot of people need to go away, so we have all sorts of travel subsidies, accommodation subsidies, things like that for people that are unable to travel to get services for themselves. A lot of the conferences that I attend by teleconference because a lot of meetings are actually held away from Cooktown, so often in Cairns they'll have a board and people will sit on meetings and I'll participate at the multipurpose health service and do that by teleconference.



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Having said that, there's other groups advisory groups and committees that I attend in Cooktown. One is a community advisory network at MPHS in Cooktown. So I've sat on that committee and we're talking about a lot of different issues. Some issues people in metropolitan areas like Brisbane would understand as well obviously, like patient safety, sharing data and stuff like that. It was interesting to listen to the presentation yesterday on the new system where people are being able to use the Internet to look at their health records and stuff. I think that's really good. The committees deal with compliments and complaints and another one in Cooktown is emergency medications. A lot of people that are on medications such as mental health issues are needing to have blood tests taken and the tests get sent to Cairns and they turn it around and sent results to Cooktown for the psychiatrists. So if people are noncompliant with their medications and run out of medication, what can you do? If you don't take it for a number of days, you have to start at the base level and they'll work you back up from scratch.

So the hospitals and that are requiring emergency medications and stuff like that in Cooktown. We talk a lot about advance care directives if you don't know what that is, it's for people approaching the end of their lives. I'll just pretty much wrap that up now. I've still got 5 minutes? Oh thanks, I thought you were trying to kick me off. I'll keep going then. Okay, fine. So the advance care directives, so that's for people that are approaching the end of their life and they would like the health professionals, family members, clergy to know what their wishes would be were they incapacitated and not able to express those wishes for themselves. So there's two different advance care directives.

The first one is if you're still able to communicate your needs and wants and desires for your health care then you can fill that form out and there's also another one if you are filling a form out for somebody who's unable to voice their own opinions at that stage, because they're incapacitated so there's another form that you fill out. Those forms are bound in law, those are heavyweight forms. Being a consumer representative for mental health up in the Torres and Cape area, it's very important to get in touch with the people using the services, the service users, mental health consumers and so I don't know if you're aware of this, but in North Queensland they've rolled out the yes survey which was actually delivered around the Cape some time ago, I think it was a few months ago and it turned



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out to be an absolute flop. Nobody filled out the forms, nobody cared too much about the services they were given, were they happy, so it didn't really work.

What they've decided to do now is to roll out the yes survey again, and it's very exciting for me, because I'll be involved in delivering the survey and in that way, I can get on a grassroots level and I can talk to people who are suffering from mental illnesses using services in remote and rural communities for me would be very fulfilling role and so I will be involved in delivering the yes survey again in November I think at the end of the year. So that way we can continue to improve the services up there, because we know what the consumers really want and the experiences that they're actually really having up there. So we're going to try that one again, the yes survey which is something very good I think if it can facilitate change. Also we have a lack of services in Cooktown and the Cape and an issue that keeps popping up and you guys may or may not relate to it here in Brisbane, is the dental and so often people have to travel on dirt roads long distances, sometimes flights, but long distances to get to those appointments with dental and stuff. It's come to a point in Cooktown that you can't see a dentist for reasons for other than emergency and you're in pain. They won't see you and look at your teeth for 18 months unless you're in pain and that's not so good really. I think more preventative dental care would be very useful. So anyway, thanks for listening to me. Again, I'm from Cooktown and enjoy the rest of your time here and thank you very much for that. (APPLAUSE)

**Dr Sean Taylor:** Just to wrap up, I'd like to thank Will and Robbie for coming all the way, coming down to Brisbane. We had our meeting and I offered it to all of the consumers reps and both Robbie and William agreed to come down and present in front of everyone. They're such a great group that I'm sad to hand over, because I'm leaving the Torres and Cape hospital and health service and moving to Darwin. I'm quite sad to see the group, it will progress with the new executive that will take over my role. The new chair, I strongly believe the new chair should be a consumer and they'll take the consumer group forward. So thank you very much. (APPLAUSE)

**Jo Smethurst:** Thank you so much. William, Robbie and Sean, that was fantastic. It was particularly nice I think to see the images of Queensland. We've seen images from



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Central Queensland and now Torres and Cape. It's great to get that imagery when we're sitting in Brisbane in a room with no windows. Thank you for giving us a window to your place.

Continued in Day 2 Concurrent Session 2 Q&A >

