Connecting with expectant parents through collaboration with consumers, Metro North Hospital and Health Service

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 particu-

lar 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 semidemocratic 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 in-depth 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 non-stop 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