Fundamentals of Consumer Engagement Training

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Breakout Room 3: 14/04, 1430-1630

Jo Smethurst: Hello, every one. Looks like the general consensus is we'll kick off 5 minutes early. So welcome and thank you for this huge response to this training at this workshop at this annual forum. Can I just say that I think that the captioning isn't coming up on the screen so if you require captioning, you can sit at the back where the laptop is and read the captioning as it's going. We do apologise it's not working on the screen. I do believe it is the only break-out room it isn't currently working in but if you do require captioning, by all means go to the back of the room and watch the laptop there. I'm Jo Smethurst.

Reema Naresh: I'm Reema Naresh. We have Suzanne Wirges staffing the yellow door.

We'd like to start the session with acknowledging the traditional owners on the land in which we meet today. I think it's really important to acknowledge our elders past, present and emerging and really embrace the knowledge that we can learn from our traditional custodians of this land, not only in terms of use of land and sea but also with our own health and wellbeing, I think we've got a lot to learn so welcome. This is a 2-hour training session, it is an abbreviated version of what we do around the State so we provide training for staff and for consumers. We travel around the State at the request of hospital and health services and provide training to consumers there as well as staff but we know there's plenty of people in our State-wide network that haven't had the opportunity to come to our training. We also have run them in Brisbane as well across the road from our office in the Brisbane City Council library because it's a nice space to hire out. So this is the first time we've run a workshop at our annual forum so looks like it a desirable thing to do so we'll note that for next year.

Health consumers Queensland is funded by the Queensland Government. We provide support and training and advice for consumers who are really interested in working with hospital and health systems and other health organisations in shaping our health system. We also provide training and support for staff and a whole range of other things

as well. As Mark said earlier, we have just launched our new guides that are the complementary guides that go along with our framework. So in the packs you've got a big Burgundy A4 framework, that's our Consumer and Community Engagement Framework. We'll be going through key elements of that this afternoon and then we'll also do some scenario-based questions and workshops so you'll get to work at the tables to come up with some questions and strategies to help you move forward even when you do sit on committees and you want to think about how can I be strategic, how can I make a difference, what do I need to be thinking about?

That's the framework. The two new guides which were in your bags, there's a guide for consumers, part partnering with health organisations. It's got a photograph of a group of people on the front. That's for you, written for consumers to help you. So this is only two hours. We're just going to skim the surface of this but know that the guide is there and there's a whole range of information and tips, suggestions and strategies in there and it was written and informed by fellow consumers who came to focus groups, told us what they wanted to know and we wrote it based around that. There's also the complementary guide for staff on how to engage with consumers. So it takes two to tango, there's no point training consumers up who are all geared and ready to inform and influence the health system if the staff can't respond in kind. So we do a lot of work with staff to build up their capacity and their confidence and willingness to work with consumers and see that we're not scary beasts because we're not, we're pretty awesome.

The first hour of this 2-hour abbreviated training session we're going to go through the fundamentals of what consumer partnerships are, who is a consumer, so the key aspects from the framework and then we're going to launch into some workshop things in the second half so you guys get to talk to each other and then we'll share back in a way that we have never had to share back before, with 40 people in the room, and hear all your tips and strategies for doing that and we will absolutely plan to finish at 4:30 so that we've got the networking drinks and things outside and that's when everyone else will finish. So who is a health consumer?

Audience Member: We are.

Jo: I heard someone say, "We all are." It's a rhetorical question.

Reema: Anyone that accesses or has people in their lives that access something that means the staff who are providing us care are also health consumers at many points in their life as well. So who's a health consumer? It's everyone and anyone. From the cradle to the grave, we are all using the health system many many times in many many ways, whether using it for ourselves or accessing it because we're caring for someone who currently needs to access health services.

So when we talk about consumer partnerships and consumer engagement, what we're really after is people with that lived experience who can help inform policy makers, clinicians, all those who get to make decisions but the consumers who are sitting there at the table with them, their primary experience is of using the system so if you're a health professional and sitting there at the table but you've said, "I've just recently had my wisdom tooth out so I can be your consumer rep on this oral health thing," we would much prefer it to be a consumer whose primary experience is that of using the service because it is very difficult for others around the table to know - if, for example, it was me, I'm not a clinician but if I was - is Jo talking from the perspective of a staff member who knows budget constraints and roster problems and other things or has she got the hat on as a consumer and talking about what consumers want? That's why we really recommend that consumer whose are sitting at decision-making tables, they are there because their primary experience is of using the system. Obviously it's useful to have a whole range of people sitting at the table and getting all the expertise and skills and we believe that everyone has a piece of the jigsaw puzzle that can help solve this massive health conundrum. Health is facing very big challenges and the only way that we can solve the very big challenges confronting health and the health system and all of us as a community and Governments at the moment is everyone that has a unique piece of that jigsaw puzzle is at the table and willing and able to share that unique piece of the jigsaw puzzle to try to figure out together what the picture looks like. We can only find a solution, we can only find that picture if everyone is working together as equals.

So that leads into consumer partnerships. So consumer partnerships really are when consumers are sitting at tables and making decisions in planning, prioritising allied health, implementing, designing and evaluating and delivering. We have a voice in all those areas. Often in the past, consumers have been used quite a lot in delivery, like how do we make this better? But a whole bunch of decisions were made back in the planning phase where consumers were not involved and so they've reached a point where it's like, well, actually if you were involved back at the planning phase we wouldn't be starting where we are right

now. So it's really important for consumers to be involved in many parts of that planning cycle.

Before we move to the next slide I would like to hear from some of you - why do you think consumer partnerships are important?

Audience Member: Grass-root knowledge.

Audience Member: I think it's important that we're all on the same page. As you said, we're trying to get all into one, the jigsaw puzzle - now, this is the start. This is the start. Let's do it.

Audience Member: Perspective of a consumer.

Reema: Yes.

Audience Member: We become checks and balances within the system.

Reema: Yes. Anybody else?

Audience Member: I think just so that excellence in clinical care is also delivered in a way that meets consumer values.

Audience Member: Sometimes it brings the perspective often when your accessing the health system you're in a vulnerable state and a clinician is not - well, might be but is not. So it's bringing that perspective too, like this is what you said when I was at this point in my life and this is what that meant. Just brings a whole other perspective.

Audience Member: Running on from that, it gives a power share in care.

Reema: It can be really disempowering, you go in at your most vulnerable and unwell and there's someone else.

Audience Member: Often it's really only the client, the consumer, that's got the big picture of how the disparate inputs are. The GP theoretically does but they don't have time to either. It's the person at the bottom of it that knows. It's a question of coordination.

Jo: You guys are already awesome at this and you know why consumers need to be involved and the difference that consumers make and we've had heard a lot this morning from the consumers who've been up on the stage about the difference that they've made. So it really is valuable and I think, Daniel, you're saying consumers have a very unique perspective because they're using the complete system that health providers don't because they're providing care here and care here and care here but for you, you're seeing the whole picture from that consumer perspective which is really rich and valuable.

So the reason consumer partnerships are really valuable is so that we end up, when we do receive care, getting consumer-centred care. So at the moment, clinicians with the very best of intentions are absolutely trying to provide us with the care that meets our needs, that respects our autonomy, respects our decision-making, but often they're constrained by a whole bunch of decisions that have been made because a whole lot of decisions were made often in the absence of consumers so that the model of care might not be quite right, the rostering system isn't quoit quite right, the length of appointment times isn't quite right, the clinic is in the wrong place. So by involving consumers in the partnerships it helps reach the bull's eye of consumer-centred care. Without consumers being involved in the decision-making at this global external level, it's really difficult for us to be able to receive consumer-centred care. Part of consumer-centred care is of course culturally appropriate care and the only people who can let a clinician know they're getting culturally appropriate care is the person themselves. The clinician isn't in a position to be able to say, "Yes, I probably culturally appropriate care," in the same way that clinicians may think they're providing really great consumer-centred care but you might be able to offer a different perspective and say, "You know what? When you went from that light-hearted conversation to talking about end of life care, I wasn't ready for it and that wasn't meeting my needs and wasn't the best way to introduce a really big topic to me." So consumers are the ones best placed to be able to say whether people are providing consumer-centred care, culturally-appropriate care, all of those things we're after.

Reema: What are the drivers of consumer engagement or partnering? Put your hand up if you were in the big hall when nagnomy was presenting, she was from the commission. I found that really interesting and useful. She talked about this amazing document. Who's seen this before? This is really amazing and what she was saying towards the end of her presentation was that there was a lot of people who didn't know about this. I started work at Queensland Health six years ago before I was in this role and I didn't even get this at my orientation. I was newish to the country and didn't get this. I didn't know what my rights were. I am from Fiji. I came from a country where we don't have the same kind of health care system so it would have been really good to know this.

I'm going to go over two important things as consumers you could know about but then when you look at our consumer guide, which is in your packs, it has a whole bunch of other documents that drive consumer partnering. This is one of them and the end result of this is that we want to have really amazing patient-centred consumer-centred care. So the aspects about this is that as a consumer, this charter summarises you have rights and you're entitled to existing health care. The right of access, safety, respect, communication, participation, privacy and comment. I could go through them individually but this is in your packs. I would love to leave it with you to read because the bigger part of today's session is we want to have lots and lots of discussions with you so that's coming up very soon.

Jo: The charter for health care rights is really useful when you are a consumer rep or consumer advocate and you are sitting on a committee and being asked for feedback on something that you haven't experienced yourself or you may have experienced but you're thinking "what more can I be is saying?" This is really useful framework, going, right, access, is this proposal that they're talking about accessible for everyone? Is it accessible for those people with vision impairments, hearing impairments? Is it accessible for people in wheelchairs? What else do we need to think about in terms of accessibility? Same with safety, you can bet your bottom dollar clinicians have got their eye on the clinical safety and evidence-based clinical care but there's more to safety than just the evidence-based thing. There's emotional safety, psychological safety, spiritual safety. This is where you can come in and talk about another aspect of safety that maybe no-one else at the table is talking about. So you can see how these rights, which is all of our rights no matter what hospital we turn up to in Australia, whether it's at Cunnamulla or Thursday Island or the Princess Alexandra, we all have

these these rights. It is a useful way for you to be able to go, right, you can tick-box things as you're going down and be making sure that the care is respectful and what does that mean? And have we talked to other people in the community to find out is it respectful of your culture and language as well? It's another way of using the charter.

Reema: I agree it's like a tool you can use. So the next thing that drives consumer engagement and partnering is standard 2. We now know that there's a new revised version of it and the big aspects that I would like to highlight with you is health literacy is a really big part of this and consumer engagement and partnering is an overarching standard so it needs to be met through every level in all eight of the standards.

The other part that I'm really excited about sharing with you is our engagement framework. This document is in your packs today. This is something that Jo talked about at the beginning. This has come through and developed with a lot of engagement from consumers and staff together. So there's four parts to the framework and, again, just like Jo went over using this as a tool to look at when you're working as a consumer or when you're providing advice and participating in partnering, you can use that as a way to provide advice. So the four parts are: Where partnering is happening; when partnering is happening; the engagement spectrum and the principles. So all of those are detailed in here.

If you look at any project that's happening and you get involved in it, you might get involved in the needs-analysis part in the top left to priority-setting, planning, implementation. You could be invited to be involved at any one of those stages. Our recommendation and suggestion is you as consumers are invited and involved right from the beginning. That's what we would like to see but it may not always be that way so it really good to know that that cycle is there and that you could be at any one of those points.

Jo: The other useful thing about this cycle - this framework was written for staff not consumers, so just bear that in mind, but it's useful to know how to use it in your work. So if you're sitting on a committee and you're constantly getting information and it's always at a certain point - say it's always focussing on the delivery part of the cycle, you could be looking at it going, "Right, that's what's missing," and say, "Can we be involved in the planning decisions that you're making before it get into this delivery phase? Or we want to be involved in the monitoring and evaluation service. We've got ideas about what's important to us and

what we would like to have measured." So it's just a way of you to be checking in on the engagement you're involved in. Is it as good and strong and as effective as it could be in this is a tool you can use to be going, right, I think we could be having conversations and getting involved in some other decisions as well.

Reema: The next part of the framework is the principles of partnership. So there's four principles - partnership, respect and dignity, inclusive and improvement. When we look at partnership - so, we're talking about meeting at the same level. We're talking about having the same respect between staff and consumers and giving advice and supporting each other through that and this could happen at all levels of service so it could be from planning, design, delivery, evaluation, monitoring. Improvement, so this could involve in terms of supporting your consumer in training and developing them and building the capacity so that they are more skilled in being able to provide advice so if this is not happening for you then this is something you can ask your engagement staff that you're working with that, "I'm not feeling confident with this. I would like more help in this. Or I more information." You can flip it around like Jo was saying, this has been developed for staff but we turp it around and you use it as a way to request things for yourself in the way you can work. Respect and dignity, again, a lot of this is around if you're feeling like it's not happening then being able to feel empowered and be able to take it back to the staff and saying these are the principles that Health Consumers Queensland recommends and this is how I would like to work… inclusive, so, if you're sitting at a table and you're the only consumer there - often this might be the case - we recommend two but there's so many different populations and diversities, it is really impossible to have everyone so then it becomes really important for you to be able to reflect and keep the voice of the consumer at the centre of the table, of the discussion. Maybe say, "Have you thought about Jamila who lives down the road? She has just moved from Iran recently. Or have you thought about Jackson? Him and his partner have just recently adopted a baby." So there's - you may not necessarily have to give advice from the perspective but you can ask questions on their part so then you're inviting an inclusive perspective in it.

Jo: Just one more thing on improvement, the principle of improvement is about making a difference and it's about improving patient care, patient outcomes, and patient experience. So we say to staff its - it's useful to

know what we say in staff trainings - if you're not really - if you're just interested in keeping status quo, if you're not doing consumer engagement because you're interested in continuous improvement, don't involve consumers because there's nothing worse - consumers are getting involved because they want to make a difference. They want to see services improved and strengthened so it's about continuous improvement and that's what this principle is also about, it's about that continuous improvement and continuing to move things forward not just accepting the status quo.

These principles - it's kind of like the values that drive engagement and we use these four principles to accept all the abstracts that came into the annual forum. We wanted to see how each of the people that had put in an abstract had met each of these four principles because we think it's vitally important. You can't engage with consumers if you're not creating true partnerships where everyone's equal. So these things are all sort of interdependent on each other, that you are absolutely including that being inclusive and including the voice of people who are often marginalised, often voiceless, so thinking about how you're going be incorporating those voices. You can't have partnership without respect and dignity and, equally, you're not going to make improvements if you don't have all those other aspect to it as well. If you take one thing from this training, remember the principles of engagement and partnerships and how you can use this to talk about if you're feeling like there isn't the respect for your voice at the table, you could say to them, "The framework says these principles are really important. I'm not feeling heard. I'm not being respected. Can we address that?" It's just another tool you can use to raise any concerns or things you've got and also as way of giving good feedback too. Like, this is a great partnership and a great partnership because of this, this, this and that. It is a nice way - just another tool to help articulate things going on in your head and your heart that you may not have the words for.

Audience Member: As long as you don't go stepping on anybody else's toes. Is that right?

Jo: Yes, and we'll come to that sort of situation in the second half of the training. You're pre-empting us.

Audience Member: Sorry.

Jo: It's great.

Reema: We're going to talk a little bit about the engagement spectrum now. This has been developed from the International Association of Public Participation, Health Consumers has modified this a little bit. There's five levels to this. So a health organisation might communicate with consumers because they want to inform us about something, so they just want to let us know we're doing this, there's a new service or we're here. You often see this in terms of posters or something on the news or on the radio.

Then there's a consult level where we want to get new information and ideas or we're seeking feedback on an issue but the full decision-making power is still with them. Then there's Involve. With Involve, there's in-depth discussion with consumers and people about whatever issue it is. The input will have some influence on the decision-making. You can see as we go from one end of the spectrum to the other, the level of decision-making or influence that you as consumers would have becomes greater and greater and greater. If we start talking about ing to have really good partnership then I would say that we want to be more on this end of the spectrum. If we think about this cycle that we talked about that potentially happens in a lot of projects and processes in the health system then you might find that you might be at different levels of the spectrum at different times of the project-planning phase and that's OK. We like to encourage and see that we become more and more - go from involve to collaborate where there's lot more involvement and then there's the next level where it consumer-led. You might hear it differently, coproduction or codesign, where the consumers come up with the idea, we want to see this different, we want to see something new, and they will come up to the health service or health organisation and initiate that process so we work all the way back down from that.

Jo: Any questions so far?

Reema: If we go back a few slides where the circle of the framework is, probably the other thing that I should highlight is you can see consumers are in the centre - individual - so that's us, any one of us at any one time. Then you can see there's service, network, system. When you become involved as a consumer, you will have the opportunity to work at different levels. It's really important to understand at what level you have been engaged at. We hope that it would be something that the engagement

stuff will explain to you really clearly and if they don't then please ask them) staff not stuff) Individual level is a lot about patient-centred care and how you're being treated. That's your personal interaction with your GP, your clinician. This is on page 14 in your framework. We're talking about service, so you might be involved with the hospital or a facility where they're looking at a particular program or service delivery or you might be involved at a network level which might be the whole hospital health service system or you might be working with a primary health network or it could be another non-Government organisation like Heart Foundation or Diabetes Australia. At a system level - number 4 - is where we're talking about Local Government, State Government or Commonwealth Government so you can see that as we get further and further out the level of influence is quite different and the way you would be engaging in your role as consumer reps would be quite different in terms of the kind of advice you'll give and the kind of interactions you'll enter into. Also gives you clues about the kind of questions you will be asking, the kind of issues you will be raising and it also will give you opportunities to really think about the different areas you can make a difference in so you might find something local you want to do and you'll work with your hospital and health service, so that's a network level. Or you might say, "I'm a breast-feeding mum and we don't have any lactation consultants linked to our hospital," so you're making a difference at a service level within your community. It is good to know that because it gives you - this is slow work so it takes a while before you see change. One of the things that having this knowledge does is it allows you to see where you're going to be influencing and how long the change will take.

Jo: And knowing where you are in the system helps you to know who's accountable. So a lot of the work that we do is with hospital and health services in the Department of Health and so the boards - so Ian Langdon is the chair of the board of the Gold Coast hospital and health service so the board is accountable for the care that the Gold Coast hospital and health service is using so it's useful to know if you're sitting on something at the Gold Coast, that's who's accountable. If you're sitting on something that Department of Health in Queensland is working on, it's the Health Minister who at the end of the day is accountable. Matthew, you're sitting on an Australian Digital Health Agency committee so the person accountable for that work, is it the Federal Health Minister or head of the ADHA?

Audience Member: The Minister.

Jo: It's useful to know where you are, where the money is coming from and the levers. That's why it's useful to ask for an organisational chart so you're really clear about where you are sitting and how that impacts on the other aspect of care in the system in that particular organisation. The second thing I want you to take out of this is that your job is to ask questions. Question, question, question, question. It could be about where does this sit? Who else is being involved? It's just lots and lots of questions. Is the role of consumers, to sort of figure out what's going on.

Reema: I think someone said create opportunities for people to step on toes. Often they will not have an answer and that's alright. You've just raised a question and you can just leave it so they have the opportunity to think about it.

Audience Member: Seed planting.

Reema: Yes.

Audience Member: Not every question is right for a male and a female.

Jo: Yes, and being aware of that.

Audience Member: Do you know where it sits in terms of reference?

Jo: I think good terms of reference make it clear where the accountability is, where it sits in the tree, and if it's not clear, always ask because it is very useful to know.

Audience Member: I'm so confused.

Jo: With something you're sitting on? It’s sometimes consumers have been sitting on entities for a while and it's still unclear what their role or purpose is because it's never been articulated, hasn't been obvious, the

terms of reference don't talk about it. It's OK to ask, "What do you want me to do? Where is this sitting? What's the scope? What's in scope? What's out of scope?" So being really aware of all those things is useful.

So the role - auntie Wynn Te Kani is one of the people on a State-wide network - all of you, I hope, are part of our State-wide network as well, if you're getting emails from us with opportunities that are coming up all the time. I liked this quote when I was talking to auntie Wynn one day on the phone and I said, "Can I write that down and use it?" She said yes. It's a message of hope. I think we're all here because we think we can make a change. If we didn't think we could make a change we wouldn't be here today. Hold on to this message of hope because sometimes this work can feel hard and it does get difficult but hold on to the hope that we can make a difference and together we can and are making a difference.

So what's your role and responsibility when you're sitting on committees, when you're at a conference, you've been invited to a forum, you're involved in a panel, you're doing some orientation of staff? And that's why it's important to ask what's my role, what do you want me to do? Your role is based on the idea that we all have a right to be involved in decisions that matter to us and can make a difference with us. It's ensuring that decisions are being made with people who are receiving care at the centre of that decision-making. So it's OK to say, "How is this going to make a difference to the people receiving care? Do we know what unintended consequences might happen if we do this? Have we seen what has happened in other States, Territories, other hospital and health services, other areas when they've implemented something like this?" So keeping the people receiving care at the centre of that decision-making is really important role that you make. Often just being there at that table helps make that happen because you're visible. I have had plenty of people talk about - you know when the consumer stepped into that auditorium had I had to change what I was going to say -

Audience Member: Good!

Jo: - because I realised I had made the consumer invisible in what I was going to say. Often, just physically being there helps change the conversation and change what's going on. We can raise the concerns of consumers, we can look beyond that clinical perspective, we can speak up and get connected with other consumers so we know what's going on across the board. We're hearing the grass-roots rumbling. The patient

travel subsidy scheme - the Queensland Government ombudsman ended up doing a big review on it but if you've been listening to the grassroots in community settings for the past 10 years, you could have known that that was a significant problem for people trying to access care when they have to travel. So it's just tapping in to all of that and raising it and Janet Cross who asked Ian Langdon that question about, "I was one of those angry consumers and I said this and did I make a difference?" And his response was, "I remember that and that ... it's raising those questions, raising the concerns from the community where we can make a difference and sometimes IanLangdon the board chair talked about someone saying 12.5% of people who use the ED at the Gold Coast come from retirement care and said it may not be the right figure but ut given him the ability to ask a question he hadn't thought to ask before. So those are all sorts of things you can do as part of your role as a consumer to be doing that.

Some of the limits to your role is you don't need to have a technical background. You shouldn't be expected to understand the clinical jargon, acronyms, all of those things. Ask for things in plain English. Be the person at the table that says, "What does TOR mean (?) Or what's - there's so many acronyms in health. HCQ's one."

Speaker: One of my pet hates, acronyms.

Jo: So being the person to say, "What does that mean?" And the consumer sitting at the table asking those questions is often really valuable for staff members who it's a little bit career-limiting if you're a staff member and you say, "Sorry, what does such and such mean?" And it could be a clinical guideline or key policy or something that they should know but if you're the consumer sitting at the table, there are no dumb questions. You can ask anything sit and helpful for everyone at the table.

Audience Member: What happens sometimes is they don't actually know the answer.

Jo: You don't need a technical background. You shouldn't be expected that you're going to be doing formal consultations. So, just because you identify as culturally and linguistically diverse doesn't make it your job to go and talk to everybody in the community who's culturally and

linguistically diverse about something that's going on at the hospital and health service. It's still the responsibility of staff to do that community engagement but you can be asking the questions of, "Have you thought to talk to cultural and linguistically diverse groups? I can give you a list of organisations you may want to go and talk to." It is not your job to undertake formal consultations and if you're a member of our network you can't speak for our network. Yes?

Audience Member: The comment was if staff don't feel comfortable to ask questions, that's a safety risk.

Jo: It is absolutely.

Audience Member: Should be improving the culture so they're free to speak.

Jo: Plenty of hospitals are doing initiatives called speak up for safety. It is making sure there's a culture where you can ask and there's a no-blame thing going on. That's a work in progress.

Audience Member: Staff can't retain everything. It's too specialised now.

Audience Member:... they're not doctors, they're the patient. I think it should be incumbent upon health care professionals to keep it simple, in layman's terms, so people understand.

Jo: One of the things we won't have time to talk about today is around health literacy and the responsibility of staff to communicate in a way that we can understand. Often when people talk about health literacy they talk about wanting to increase the health literacy of the people using the services. We can flip it and we can help improve capacity of staff to be communicating in a way that is really obvious what they're saying and what we need to do and those sorts of thing those in our extended training we do talk about health literacy but we won't be today unfortunately. It is very important. One aspect I will say is that the Australian ... have done lot of work on health literacy and 60% of Australians have a low health literacy so just remember that when you're

sitting on things and you might be reviewing brochures or websites or apps and thinking 60% of people have low health literacy. Is this going to work for those 60%?

Audience Member: I want to share at on health literacy. I had an experience a month ago where I was in Lady Cilento with my son who was post-MRI, under general anaesthetic and an ophthalmologist was coming in to do a review, have a look at his eyes with his fancy headgear. They failed to talk with me beforehand. This doctor was walking and I called his name and he kept going. I called three times and got no reply so I yelled out, "Hey, doctor, talk to me. Standard 2!" He turned around and shook my hand and apologised. If we don't speak their language, just throw Standard 2 at them and they will respond.

Jo: Standard 2 is a particularly useful way of getting attention. So there's lot of ways consumers can be involved in helping shape and influence the health system. Many of you - I look around and I know you're sitting on committees, could be safety and quality committees, consumer advisory groups, but we have probably all filled out feedback forms about the care we've received and that's another valuable way. You can also have consumer reviewing de-identified feedback forms. Had a story from an in-patient mental health card at the Royal Brisbane Hospital, it has a carers committee that provides support and advice to the workers and that particular carers committee would look at the de-identified complaints. One of the complaints that had been made was blue phone on the ward wasn't working. So they also on the table had been taken to maintenance to have the problem fixed. The carers identified this was not a maintenance issue, it was about connection and communication and this was the only way those people on that ward could communicate with their family and friends and others while they were in that in-patient ward so they got it escalated so it wasn't just a maintenance issue that had to be fixed in three days, it was about wellbeing and safety and it got done very quickly. So, again, that complaints form or the feedback form is a useful thing for consumers to be able to review as well to see what's going on.

Consumers are often used to review brochures, apps, websites, patient information, consent forms, you name it we need to be looking at it because we need to be able to read and understand them if they're being designed for us. And Carolyn Waterman who spoke first was talking about being involved in the orientation of new staff in Caboolture and lots of hospitals are having consumers sharing stories, takes and

trainings and it's a really useful way to ground and anchor clinicians, particularly new ones coming into your organisation that, A, consumers matter, B, they've got really valuable things to share, and I don't know past A, B, C because I can't see off the top of my head. There's lots and lots of different ways that consumers can and are involved in health organisations. We've had consumers sitting on research grant panels and deciding what researchers get the go-ahead, get the funding. We've had consumers sitting on the recruitment panels of senior leaders in the hospitals and it's a really effective way of letting people know consumers absolutely matter and we need for people to be able to communicate and respect the views of the people that they're providing care for. I think that what we're doing now is only limited by our imagination and as staff grow in confidence and they see the results and as we see the results and get more confident as well, I think that what we'll do in 10 years time is going to look very different to what is currently happening. I've got a great deal of hope that consumers can be embedded as Ian Langdon said this morning, all the way through the system in many, many different ways and there's also an increase in consumers actually being paid employees to peer support workers, not only in mental health but branching out into other areas of Health as well because it's very important.

Reema: What we're going to do is look at effective tips and practical strategies in terms of what you can do. I think we're starting off by watching a short video.

Jo: The video was produced by health issues centre in Victoria, our sister organisation. It's tongue-in-cheek so take it with that in mind, it is just important to say, and it's fun too.

Video Transcript:

Narrator: The video that you're about to see could be considered to be a crime against acting but at its first performance many people asked us for a video of the sketcho that they could use it for training. As that much more famous playwright, William Shakespeare, said: If be offend, it is with our good will, that you should think we come not to offend but with good will.

John: That pretty much wraps up that item except how do these new national standards impact on listeners?

Mitsy: Good grief, those national standards, all we're hearing about at the moment is consumers, consumers, consumers. How on earth are we meant to run a health service if we have to keep worrying about consumers all the time?

John: We have a consumer engagement officer?

Mitsy: We do.

John: Consumer engagement. Interesting idea as long as we don't have to get married. I think that wraps up that item. Let's move on to the rest of the agenda.

(knock at door)

Matt: This is Angela, our new consumer rep. Sorry we're late. We couldn't find the meeting room.

Mitsy: I sent the directions out with the agenda.

Angela: I didn't receive anything.

Mitsy: I emailed it to everyone half an hour ago.

Janet: I got it.

Angela: I wasn't sure if this is what I wanted to do in the first place. I mean, what do I have to offer in a meeting like this? It's pretty obvious it wasn't important if I got the agenda or find the meeting room.

John: We can find some spare chairs, please sit down. Excellent. An agenda. Have we got a spare agenda?

Janet: Here's an agenda for you for the meeting.

Mitsy: Just look on together.

John: So, let get cracking.

Matt: Perhaps we could all introduce ourselves first.

John: Good idea. I'm Matters, John Matters, chairperson of this committee of course. Member of the board. 25 years experience in health care management, MBA and I just finished a PhD in time management.

Mitsy: I'm from the corporate unit. I manage communications, marketing and event and I keep an eye on the volunteers to make sure they're doing the right thing by the organisation.

Rosa: I'm director of clinical governance, quality innovations and feng shui. I was a nurse in a former life but now I mostly deal with issues of current relevance and political correctness and I attend lot of meetings.

Janet: I'm Janet. I'm from IT. To tell you the truth, I have no idea what I'm doing at this meeting or why there's a consumer showing up here.

John: OK, and who do we have here, Mark?

Matt: Matt. I'm Matt, the consumer engagement officer. This is Angela. She can introduce herself. And

John: Welcome, Angela. Great to have you here but we are running slightly behind time given you guys were late. We can do introductions at the end. So let move along.

Angela: What a relief, he wasn't even interested in knowing what I do or who I am. What was I going to say? I'm just the daughter of a patient here and I have roles and responsibilities here but I'm nobody.

John: OK, let's resume. Do we have information for new members?

Mitsy: Yes, of course. Here we go, Angela. Just quickly read through that and that should answer all your questions.

John: Excellent. Alright. So next item on the agenda is the report pages 12 to 70 really were the guts of the matter. Some recommendations there. I think we should just move on, I don't think it there's anything to act on. Everyone happy with that? ?

Angela: No, I don't know what the requirements.

John: Vargo came here, did an ought, did a report. There were recommendations and we're considering how we should respond to the report. I was suggesting we just note that and move on. Are people happy with that?

Angela: Yes.

John: Great. Next item?

Mitsy: Next item is the MoU from the CEO, we spoke about this with the meeting at ICT and CG about the LGA and VPSM data a and sinkerisinised input with VCH directives in order to have CIM inputs fOred for planning section for ASQCH standard, that's it, really. Any comments?

John: Pretty straight forward. AOK to me.

Rosa: I'll get on to it ASAP.

John: Janet?

Angela: This is exactly what I thought it would be. A group of people sitting around a table talking in 3-letter acronyms. I have no idea what they were talking about. What really concerns me the most is how does this have anything to do with improving the care of older patient s?

Rosa: I know exactly what that woman is thinking - she's wonder figure this is all we do at Health Services. That we talk about reports and we promise to write reports and go to meetings and then go to more meetings. This isn't why I became a purse 20 years ago.

John: Next item is the community information session for the Arabic patients - no, it's for the Arabic women's group to increase the awareness among Arabic women of - what's the focus of this? Angela, what do you think?

Angela: I'm not sure. This is my first meeting. I don't know anything about the women's group.

John: Sure, but maybe drawing on your experience as someone who can represent all consumers. You're a woman from overseas.

Angela: I'm actually Australian. I was born in Melbourne and I'mer not an Arabic woman. I would suggest actually having a chat with the women and seeing what they think.

John: Well, OK. Interesting.

Matt: This guy is such an embarrassment but at the same time it not as easy as Angela might think. Who was got time to get around to every call group and ask their opinion?

John: Interesting idea to consult the women. What do you think?

Mitsy: I'll ask my PA about it. She's from Thailand.

Rosa: Perfect.

John: Excellent. The last and most important item is strategic plan. Obviously if we're going to throw this together we need to plan this and I'm suggesting a planning meeting at which we can work out how we prepare an operational plan in order to plan the various subplans, strategic plan and add them together and add the final strategic plan and obviously we need to plan plenty of time there for consultation.

Rosa: So, John, when's the strategic plan due?

John: Um ... Friday. Still got four days left.

Mitsy: Great. OK, I'll have my PA send you all an invitation for 7am breakfast meeting tomorrow so we can sort it out before lunch and send over to marketing and they can fix it all up.

John: Yes, I'm free. Beautiful. Alright, I think that's all. Thanks very much, everyone, for your contribution. We'll meet next time, I guess.

Angela: I actually wanted to raise some feedback I got from patients at the emergency department, some of the suggestions they have in mind.

John: Terrific, Angela. We have a process for putting items on the agenda. If you read your information pack you'd see that. You can just email Missy and she'll put it on the agenda for next time or maybe the meeting after.

Mitsy: Three months. That will be fine.

John: We'll be ready to hear your feedback and input. Thanks, everyone. See you next month.

(End of video)

Reema: What did we think of that?

Audience Member: It's real!

Reema: How do you think the consumer was feeling?

Audience Member: Mind blown.

Reema: Completely beside herself, yeah.

Speaker: As one of my friends, Julie, knows, acronyms drive me crazy. I just don't get them.

Reema: You know what's really interesting is - last year, about a week before the annual forum when I started working at health consumers Queensland and joined this amazing team, within the first two months of my role I ran lot of focus groups because I was very much involved in writing the guides you have in your pack and as part of running the focus groups together too gather information from consumers, one of the things I noticed was really, really experienced consumers were talking to me in acronyms that I was asking them, "Hold on, I need to ..." so I was writing them down and trying to figure out what it was or if my colleague was with me I'd go, "What does this mean?" Because they've been in the system so long or working for so long that even they're starting to use that language.

Audience Member: It does speed it up. It's good when you sit down and write a report, you kind of need them, but it's about explaining as you go. Even doctors in one department won't always know the acronyms of another department."

Reema: What do you think the staff could have done differently to make it better for the consumer? What do you think are some of the things?

Audience Member: They need to make the agenda first, warm welcome, introduction. Thank you for sharing the time, acknowledging here.

Audience Member: Sign to the room.

Audience Member: Contact the consumer before the meeting.

Reema: That would have been really good and tell the consumer what the meeting was about. Anything else? Peek speak being expected that because she came from overseas to know.

We're giving out sheets to run an activity but as a consumer I encourage you to understand. Understand your role, understand what level of influence you have, understand where in the spectrum you can give advice from, understand what part of the project planning cycle you're in. All of the different tools we've talked about and pointed out. Get a really good understanding on what you're getting involved in. Become really informed. Be informed about your role. Be informed about the project you're working in. Be informed about the health service you've become involved in, the people you're working with. Then speak up about it. Sometimes you have to ask the hard questions. Sometimes you have to step on people's toes, politely. Maybe, maybe not. It is about being able to speak up and raise the voice of the people who are not present. Network is another thing. Really important thing to be able to do. Speaking up and asking questions and then as well as networking with the people you're working at at that table, in that committee, also within the service or the system which supports you, the network and other consumers who are within that service because they will support you. Someone who's more experienced will mentor you or give you advice or tips you may not have thought about. Remember that consumer partnering is about relationships and investing and spending time in building relationships to support your role which allow you to give really tough advice, Frank, forth right, honest advice if it's based on someone that you've if vested time in. It's a lot easier to say something to someone and give constructive feedback if you've spent time and have a relationship with them. It takes time. We've mentioned that before. Some of these changes may actually take a lot longer than your tenure on a particular role you've signed up so keep that in mind. It helps sometimes because it's frustrating, you want to see that change, you want to introduce something amazing and it's a big system you're dealing with so

it takes time. And I will leave you with taking care of your health and your wellbeing.

So, as consumers, as health consumers, we all have our own health issues we may or may not be dealing with or someone that we're caring for, so remembering to take care of yourself, your own health, making sure you're eating right, exercising, feeling repsed and doing all those little things you need do do so that when you turn up to whatever you have decided to participate in, part in, that you are able to give your best but then if you're feel that you're not able to do that, also remember to - and because you've invested time in those relationships, be able to say, "I actually can't come today. I'm not well. Or this is not working. I need to do it differently." So being really cognisant of how things are going for you is really important as well.

Jo: We are just flying through all that and rest assured that if you come to a longer one we get to have more time for you to digest this, apply some of this information but what we'd love to defor the next hour is give you the chance to put some of this into practice and use some of the experience and expertise and skills and strategies that you've all got in this room. We absolutely respect and know there's a whole bunch of knowledge in this room. If anyone doesn't have a pack, we'll take down your names at the end and send you a pack. In the packs, there's a handout called scenarios and that's what we'd love for you to workshop together at each table. I think there's six or seven scenarios there. As a table, decide on two or three you're going to work on. I think we've got about 30 minutes so try and spend 10 minutes per scenario. If you get a bit bored, move on to the next one and do something else. We'll keep the energy up. We've got more paper, more pens. This is a chance to read the scenario and think, right, if I was in this situation what would I do? So is everyone OK with that? Has every table found at least one handout of the scenarios? And those of you who aren't at a table, if you want to join a table, feel free to join a table. Choose two or three scenarios. We don't expect to do all of them. Maybe some tables might want to work their way from the bottom up because the plan is to then share back with everyone so we get to hear a little bit of everything.

(group work)

Jo: There's been lots of animated conversation. We're keen to share with the entire room all the strategies ideas and thinking that you've had

so we've got a microphone so whoever's going to be the speaker at your table, if everyone could speak clearly and slowly so that if anyone has any hearing impairments everyone can hear and if there could just be one person speaking at a time so that everyone can hear all the great ideas that you've all had today. So I might start in the middle and work our way out.

Audience Member: They nominated me because I don't think they can read my writing. This was a combo of scenario 4 and 6 which was you're feeling a bit isolated and lonely at the table and not valued. A few strategies - I'll start with providing support to the consumer before, outside the meeting, like before you get there. Having an induction, a chat, why are you there, what's the committee for, what's your role, what might you expect, are there any minefields? Are they there as an equal or just ticking the box and understanding what level of influence you actually can have. Training for staff, the common theme at this table was - I said who were the worst offenders and clinicians and senior executives came up who would have thought! They're often removed from the topic tare talking about and don't always understand the role or importance of the consumer. Quite often people at the table were the only consumer. They have a minimum of two to support each other, strategise and back each other up, whether that's patient or carer didn't matter. Having paperwork and discussions in simple and practical language was helpful meaning the chair - meeting with the chair separately if there's sensitive problems. Acknowledging and hearing difference of opinion. We don't know everything, neither does anyone else. Having check-ins after meeting, networking with others if you're presenting issues on behalf of other and reviewing the processes regularly.

Jo: Anyone else at the table want to speak? Awesome. Thank you, middle table. I might go to the front - did any other groups also do four or six?

Audience Member: Yes.

Jo: Let's go to this back table and maybe you could share what you talked about. if you've got something the same, maybe don't repeat it, tell us something new and maybe you can move on to the next thing you talked about as well.

Audience Member: In reference to number 4, specifically when faced with needing to state a difference of opinion, instead of perhaps struggling with the personal of that but keeping it in consumer language and saying how can the consumer voice be heard on this? We're sometimes taking the 'why' out, can be more empowered the 'why' statements when we have the confidence for those are very empowering. To refer to the charter and sometimes keeping that as a visual cue rather than if we're actually speaking it but just to point to it sometimes could be useful and then if you're feeling uncomfortable but to run through it and go which of these am I not feeling supported in right now? That one. OK. And perhaps explain why there's a difference of opinion if it comes from a culture or ability perspective. A request of the chair offering everyone a voice to help to validate our position and, in doing that, reduce the sense of isolation and if you need to prepare the chair in advance, if you wish to address a particular issue you might feel uncomfortable with, but that comes to the relationship-building anyway in advance. We spoke a bit about using visual or aural cues as well as written statement because there are so many ways to communicate.

Jo: Do you want an example of the visual one?

Audience Member: In a meeting, people are talking - in a meeting I would be quite anxious myself so to get attention I wouldn't yell out, I would put my hand up and get that attention and then the chair would actually acknowledge and stop and then that gives me the opportunity to speak. That's the visual cue, just to go, "Sorry, I have a voice."

Jo: That's a nice one. I heard it at the table so I wanted you to hear that one.

Audience Member: If it's a particularly large committee and we are the only consumer, actively request and recruit other consumers to support our endeavours.

Jo: Awesome. Do you to do another one of your scenarios? Maybe choose one of them.

Audience Member: We spoke about number 7. This is real-world stuff. Day's been massive, kids everywhere, bad news and then have to turn up to a meeting and function. The first thing we hoped for, which is not always possible, is keep calm and possibly carry on but acknowledging where we're coming from. With a goal to clear our head as much as possible of the day's dramas but to keep it really back to nuts and bolts as well, being hydrated and nourished because you can't be effective if you're effectively running in starvation and survival mode. Whatever space you need to create for yourself, be it take a walk, 5 minutes of mindfulness, whatever those training skills, pull those in to reduce the existing stress levels before we enter a meeting and add other stress levels and to be mindful of the meeting zone and what that feels like in ourselves because we have to enter that space internally in order to be effective. We spoke about the importance of fining a safe person in that arrangement to possibly have a quick debrief before the meeting to download some of that personal stuff that if you find you actually do have to leave there's a person who's cued in to why that's happening. We also spoke about the usefulness of shifting from self to other if you happen to encounter, by arriving a bit early, having a coffee or whatever in the patient lounge or in the transit lounge and fining somebody to speak to and having somebody else's story and immediate way helps to remind us why we are doing this. It's not just I, it is meeting other consumers we're working on behalf of. And, importantly, knowing when to say no and getting better at knowing when we shouldn't attend that meeting because sometimes you can't put those things out of your head and that 60 minute or however long of those minutes could be better spent elsewhere.

Jo: Awesome. Great. Can I just say you guys are awesome interestingly, I'll share with the family advisory counsel at children and health Queensland, it's a consumer group so there aren't clinicians on the group. They start the meeting with a temperature check of where everyone's at and it's about how you're feeling so it a safe way, they do it every meeting, but the members of the group know where people are at emotionally so that that means it's a way of helping you manage that situation as well. Who's going to speak at this table? James from Townsville. Actually, North Queensland's getting a bit of a voice in here.

Audience Member: Number 6 was the lone consumer. We got negative feedback on how we do it without damaging relationships. We said first there should be more than one rep on the committee, minimum 2. And

there should also be agreed there should be a minimum number of reps on the committee for when major decisions are made. If there is only one on there shouldn't be a major decision made at the time anyway. When it comes to actually giving the feedback, wording carefully, using tact. You can actually add feedback without being a total ... about it. Another way of giving feedback is saying something good followed by the bad thing and finishing on something good again. At least end on a positive. If you've got something you think has been negative in the meeting, try and find something good to say so that the last thing you say wasn't that. Frame back the terms of reference and values in the meeting. Preface anything you say by acknowledging the chair. Also, remember that the feedback you're giving is about a process within a hospital not about individuals. You're not singling out any one person and you're talking about the way something is done within the health service not about what someone has done.

Then it's kind of linked with number 1 as well. Number 1 was you're at a meeting, it's getting heated, you feel a bit intimidated so what can you do? We said, one, try to keep calm because having another person there getting heated is not going to help matters very much. If you're confident enough, speak up and let them know. If you're not, you can go to the chair after the meeting and let them know and discuss it. Let them know how you felt in there. If you can, humour always defuses a situation. You can break a bit of the ice with that. And also acknowledge the opposing views causing the tension before you speak and say something. Acknowledge everyone's point of view.

Jo: Awesome. Thank you. We sometimes have consumers call us because it's about giving feedback and they've done the sandwich so well that the staff haven't heard the bad bit in the middle. Sometimes you need to think about - they say, "I frame it so nicely that they don't realise I'm being critical." It's a balancing act about how to make sure what you really want to say is being heard but they understand it is said with the best of intentions and it's about improvementism is coming back to the principle about continuous improvement and making a difference.

Reema: There's a clipboard going round if you would like a copy of the discussions of the strategies, I'll full all together and email it so pop your name and email address on.

Jo: Front table.

Audience Member: We found ourselves looking at the intersection of the different points and noticed our conversation was jumping from one to the other. In particular we looked at numbers 4 and 1 and found ourselves moving to number 5. A lot of what we discussed has already been mentioned but one story we really got interested around number 5 was -

Jo: Can you tell us what number 5 was?

Audience Member: There is no Aboriginal and Torres Strait Islander rep on your committee. The project will have effects for this community. You are asked to speak about the likely impacts but you know you are not a true representative for this group. What do you do in this situation? So the story I told which Roger really liked was imagine an old-fashioned board meeting where it's all middle-aged white men and in comes the first woman to sit on that meeting. She is not representative of all women. She is not representative of our diversity and perspective and opinions and ideas but she's in there and she is going to start planting seeds so if there's no Aboriginal person sitting on the committee and I'm sitting there then I could ask questions around when we might get - where we might bet those perspectives from. I might know someone in my network I could talk to and invite their opinions to bring back or send through via email after the meeting or they might say, "I've got someone on staff who's Aboriginal, maybe I'll ask their opinion." It is about identifying we can ask a question without being the person that represents them. That came to mind also in looking at the diversity of Aboriginal and Torres Strait Islander perspectives and languages and what that represents. It is just opening that door to have those conversations because it's the most important thing we can offer.

Also, when we do open a door to something like that, especially if we're not the representative, just say, "Make sure that's in the minutes," that way we leave a paper trail. And check the minutes at the end. Make sure you see it with your own eyes in that email. Follow up your work is basically what that is. Don't assume they'll be accountable just because they nodded and smiled. We're all human. They're not doing it deliberately. We're tired.

The paper trail is something that I've used a lot in my own personal world and we use this in relation to when we - numbers 1 and 4, when there is a trigger or a heat or a disagreement and you need to express

something but you're either frozen for whatever reason or angry and don't want to come across that way. Doesn't matter what your reason is but one solution is to say, "I'm feeling triggered, can we come back to this later?" Or, "I disagree with this. I would like to express this to you. Could I grab your email addresses? Could I dot-point you and tell you how I feel about this?" And this is an extra trick of mine. I would like to CC in extra people. That makes them accountable. If you've got someone cranky on that board, how about CCing in their boss. Sorry y thought it was the right thing. I Cced in someone from HQ, my friend Melissa, she's mentoring me. I hope that's OK. If it is about communication and engagement, we are allowed to bring in our own team. Be transparent. If you've done something wrong, say, "Sorry y stepped on your toes, I'm clumsy." That's OK. I think they were the main point we had that hadn't been mentioned by other people. Another example we looked at which Sandra brought up was when there's an ongoing problem and how frustrating that can be. The example she gave was people who were using drugs, who were in a residential proper, who were connected with Queensland Health or a service and wanted money for their bond to keep being paid yet they weren't - there was complexities around that. So why not just say, yes, you can continue to have what you ask for but we're going to offer something else as well. If you come along to this program, whether it's an educational program for self-care or whether it's rehab or whatever that program s yes, you can have what you're wanting, consumers , but you have to do it on these grounds which is for your own educational benefit and help you move up Maslow's hierarchy of needs out of survival. Showing how you can compromise rather than just seeing a problem. We don't become like them, the people just saying no. We're offering solutions.

Preventative planning. Get a hold of who people are and get your own items on the agenda. That was really huge. We've all mentioned that. If you're feeling unheard, this was in the case of number one, just be really clear, "I'm feeling unheard." Use those words. They can be really strong. Anything else to add? Thank you.

Audience Member: I would like to add to the number five scenario, I really hope that would never happen in this day and age, that they would be designing services for cultural groups and not involving people from that culture. Surely you would have the right to question and say, "These people need to be involved."

Jo: Absolutely. I think for all of us as consumers, we need to be careful that we don't speak for others, that we enable others to have a voice as well. So it's really important that we don't pretend to know something that we don't know and to say, "You need to speak to this group of people," whoever they are. The back table. Who's going to be the speaker?

Audience Member: Obviously, everything's basically been said so I'm going to out a couple of things in here we mols made mention of. Question 6 was you're a lone consumer and one of the things was just to speak from the lived experience and then your information will flow from there so if you're feeling intimidated, just remember your experience and speak from that lived experience. That was question 6 and we did the positive-negative-positive sandwich. We thought we'd come up with that so, yeah - not initially, but question 7, someone mentioned if you need to go to the meeting because you've got FOMO, fear of missing out, make sure you take a moment, mindfulness, a bit of a check-in and check-out process, so the 30 seconds, have a breath and in that 30 seconds you can say a couple of words of how you're feeling and then at the end you do the same, do a bit of a check-out and everyone does the check-out and check-in and in question 7, being purposeful, careful and self-awareness and the responsibility knowing and being aware that you may actually be transferring some of that distress to the rest of the group and being aware of that. But part from that, there was - apart from that, most of everything that was said we've also got on here. Question four - focus on the problem and not the person, so people are animated in the room, remember what the problem is and step back from the person.

Jo: I really like that, being purposeful and careful, because it helps you stay on what the issue is and avoid getting into that he said-she said blame game. It seems like one of the biggest things from all of this is communication, communication, communication so it is about communicating well, building relationships, building rapport, and just keeping an eye focused on your end goal so that you keep focused on making a difference for others, receiving care in the system or whatever the case may be. I think that goes a long way.

Audience Member: There should be no surprises. If you've got something to say, whether good or bad or whatever else, in most cases just make sure there's no surprises, particularly to the chair of that meeting.

Jo: That's nice advice. If you think you're going to say something that might be a surprise, maybe pre-warn the chair before the meeting. One of the key things that consumers say to us that happens - so, Suzanne's done this beautiful graphic for closing the feedback loop - is often what happens is you invest a lot of time, skills, expertise, heartache into giving feedback about something and you don't actually hear what happened at the end. One of the women who asked a question in Hall A, I said to her at lunchtime, "What a great question." I asked it because I - she said I asked it because I never knew if I made a difference. It is for the staff it is important to close the feedback loop. You said this, we heard it and this is what we've done. Often staff are a little reluctant to close the feedback loop because they haven't do what you have asked them to do but it's so good to hear why, so a couple of years ago - I use this as an example, it's not health related but my daughter wrote a letter to the local counsellor asking for a skate park down the road and the person who got elected remembered that letter and a year later - he had been in for a year, he wrote her a letter, this 9-year-old, a letter to say, "I asked for a skate park, council said no, this is the process that's used too, res the reasons why, I'll try again next year . He was educating her in this whole process so that that meant next time she knew when had to put the letter in, when they do the rounds, so it's all about the education process. So if the service can't do something, they can inform you why they can't do it. What's going on? Is there another project that needs to be done before the one that you really want to get done? Whatever it is it's about educating and informing you so that you're on a learning game as well and you can keep learning as well.

Reema: Just reminding everybody that the clipboard is going around. I will collate all of the amazing strategies you've shared and send them out to everyone who's listed their name on that.

Jo: Daniel, you've got a question?

Audience Member: Yes, I suppose so. This is probably the most consumer-centric session of the thing as far as I can tell anyway, we can bring good will, we can bring our lived experience and stuff but I think there's lot of skills involved; does anyone know if there are actually formal training programs for consumer representatives? When I look at it, it's like, oh, well, this is what you do in your organisation to develop it

but where is there somewhere to go, "I want to be a better consumer rep?"

Audience Member: We're in it.

Audience Member: That's what I'm saying. Is this it?

Audience Member: This is as good as it gets.

Jo: The good news is on that, health consumers Queensland has been running a fundamentals of consumer partnerships and we've been travelling around the State providing that. We have a whole new suite of training modules that we can now offer. Reema's going to start handing out a yellow form. Thank you very much for that question, Daniel, it is a nice segue into if you can please tick some of the ones that you are interested in. These are modules developed by Health Issues Centre in Victoria and there is one that's a 3-day consumer leadership training so it's not - it's accredited training but not part of the VET system but it's a 3-day course. We're hoping to run it in October. There are fees attached to these so ideally we'd love the health organisation that you're partnering with to recognise the value that you have and you bring and that they would pay the fees associated with this. So if you want to tick which ones you would be interested in and leave them on the table, we'll be collecting them. Let others know as well that these yellow forms we're going to have on the table tomorrow and let other people know. And if you're not partnering with a health organisation at the moment, just leave it blank. That's fine.

So to summarise the training, just remembering it was an abbreviated training. We've gone through what are consumer partnerships, who is a consumer, we've talked about key elements from the framework and you've got the framework in your pack, you've got the new ideas for consumers that you can read at your leisure, dip in and out of as you like. We've talked about the roles and responsibilities of consumers and had a really great session on some really effective strategies that you guys have come up with youricism so there's power in coming together with your peers and working out ideas and collaborating together to try to overcome any barriers you're facing, so always remember there's power in numbers and your peers have a lot of expertise, experience and just a shoulder to cry on every now and then.

So I would like to thank you for coming today. That ends the training but there are some messages that I would love to give you today that are in my notes for tomorrow. So, at 4:30 which is any tick of the clock, we've got drinks and nibbles - is it nibbles or just drinks? There's networking outside and we would love for you to continue these conversations you're having here at the table, swap phone numbers. I've had a question about what coproduction means. There's lots -

Audience Member: Sorry, I can't hear.

Jo: There's lots of different words to describe coproduction, co-design, participatory practices. It essentially just means producing and designing things with the people who are using it not just the providers of it. So in a health system setting, it's this, it's consumers sitting together and sitting with clinicians and bureaucrats and policy-makers to help design frameworks, policies, guidelines, new models of care, buildings, the whole lot. That's what coproduction means.

Reema: At the end of the spectrum, we were looking at the spectrum, we had inform and then the other end. So, let me give you a preview into tomorrow. I read it here earlier. So, tomorrow there are lots of presentation happening - networking drinks are going to follow after this from 4:30 to 5:30. We look forward to wining down our first day with you and welcoming you back tomorrow to celebrate the consumer-led award winner. So this morning we kicked off with the partnership award and tomorrow morning we kick off with a consumer award. So that consumer get to do a presentation like today and I really loved that session this morning. Did others?

Audience Member: Yes.

Jo: Tomorrow we've got 16 abstract presentations. In your bags we've got programs and it details what are those presentations are. You amight want to have a think to plan your day tomorrow, what you really want to go to. We're encouraging people to stay in the session that they're in. So a session might have two presentations going on so it's just to remove traffic going backwards and forwards and for people to get the most out of it. The sessions will run tomorrow, you'll hear from

someone, you'll hear from the next person and then there will be a joint Q and A at the end of that. So that's what's happening tomorrow. I have been told I have to keep you here for 1 more minute. Anyone got a joke? Actually, what would be nice is what are some of the highlights from today?

Audience Member: Bill and his wife, the very, very first one.

Jo: Carolyn.

Audience Member: Yeah. That smile on that guy's face never left and I was really taken by that. He had 12 years - he was very lucky to have 12 years. I only had five weeks with mine from the time she was diagnosed to the time she passed away. 5 weeks.

Jo: One thing I didn't talk about in the training is it's OK for us to talk about love at the table. It's OK for us to start crying and a couple of years ago a group of consumers went to a strategic planning that ended up with a 10-year vision for Queensland Health and three consumers got to speak 10 minutes each, so 30 minutes in the morning and it absolutely changed the mindset and heart of everyone there and clinicians and policy-makers who were there said, "We've never been at a Queensland Health event where people talk about caring for each other, people talk about love," and it's because the consumers got on the more than that morning and talked from the heart about things that really matter. The other role you have is to bring love into the room. On the flip side of that is death and it's OK to talk about death as well and to have a respectful death. So the work we do is really important and really crucial and it is heart work so take care of your heart and make sure your heart stays OK as you do it. I think that probably wraps it up. Did anyone else want to share one or two more highlights from this morning?

Audience Member: I like the statement collaborative relationships is where the magic happens. They said it in Carolyn's talk. It's actually where the magic happens.

Jo: In collaboration, that's where the magic happens. Absolutely. I think part of this is stat don't necessarily know what they're going to end up

with – staff. That's where the magic is. For them, it's letting go of control. When you're working with consumers you don't know what the end product is going it be and that's where the magic is. It takes a little bit of "I'm OK", letting go and being a bit vulnerable that makes this work so well. Well, go out, mingle, have a drink, enjoy and thank you.