

Transforming Culture: CHQ's ongoing community and consumer engagement approach, Children's Health Queensland

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

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

TANIA HOBSON: Thanks Keren and thanks for the warm welcome. It's a great privilege to be invited to talk to you all today and I'd really like to acknowledge my colleagues back in Children's Health Queensland for their ongoing commitment to the work that we're doing and, of course, our consumers, some of which are on the front table here. Today we really wanted to give a little bit of a snapshot and talk about from a consumers' perspective what we're doing at children's health Queensland to transform the culture and drive improvement around patient-centred care. I'll provide an introduction to CHQ talk a bit about our consumer engagement strategy which was announced late last year, and talk about some of the ways that consumers are involved in our service. Keren is going to provide a perspective of a consumer, a family member of a child who was an end user of our service. Keren is a cochair of our family advisory council. Then we'd like to finish talking about some of our initiatives that have been led, in fact, by consumers in our health service that we're very

proud of. We might have introduced ourselves a little bit. My name is Tania Hobson, I'm the executive director of allied health at Children's Health Queensland, a speech pathologist, but have the great privilege of leading a consumer engagement strategy. I connect people and I advocate for consumer and community engagement. We've got people at all levels of our organisation involved and doing great work. Keren, would you like to introduce yourself.

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

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

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

various strategic projects that we're working on together. I'll hand over to Keren to talk about the Family Advisory Council and importantly, her perspectives on being a consumer in the health service.

KEREN POINTON: Thanks, Tania. So our Family Advisory Council members are parents of carers of children who have firsthand experience of Children's Health Queensland services. Our membership is open across the whole State and we have many backgrounds, many experience. Some with young kids, some members with older kids, some members with foster kids. Grandchildren, as well. We have regional families and members from all different backgrounds, culturally as well. Diversity is one of our key strengths. We are unpaid volunteers and are often struggling children, both well and unwell and many members also have full time employment and significant work and other commitments. One common thing we're grateful for the care that we've received and are passionate about giving back and helping to improve services at Children's Health Queensland working with the organisation, with an emphasis on family-centred care. A very positive step in 2016 was being supported by Health Consumers Queensland with consumer engagement training. As Tania has mentioned, there are many examples and a growing list of consumer engagement and action at CHQ including increasingly consumer-led design. Next, I'm going to give you the consumer perspective on some of those activities and how that is going and the lessons that we are learning. So the consumer perspective, working with consumers is a given, but can often be tokenistic as health care providers struggle to find meaningful ways to collaborate. I'm sure many of you can relate to that comment, because it isn't always easy. So how to help with that? Well, small things make a big difference, so one of those is about setting clear expectations and that's not just for consumers, but that's also for staff. So for staff it's asking, what engagement are you after? Is it a oneoff piece of engagement, is it ongoing? How many meetings, how long are the meetings, how much prereading? A key ingredient for our Family Advisory Council was actually speak and meeting prep actually by the cochair or our executive sponsor, making sure that our speakers that were coming were very clear about what they were after from our Family Advisory Council, but also that we'd given them a heads

up on the issues that we had and the questions we wanted answered. This is effective in making sure it's not just a talkfest, but we get real solutions and real momentum to resolving issues. For consumers, expectations are about are you there as an individual and your own specific circumstances, or are you there to give your feedback and discuss and raise systematic issues beyond the individual at the service department or organisational level? In regard to setting expectations, there's a lot of power in effective terms of reference and ideally, that as consumers we've had codesign of those terms of reference. For our Family Advisory Council we have a very good terms of reference that we've codesigned and having the mandate and support of the chief executive officer for Children's Health Queensland is very powerful. Another effective strategy to enable meaningful ways to collaborate is to apply family-centred care principles. What a difference family-centred care principles make in the delivery of health care, but they are also equally important when engaging with consumers. So, family-centred care principles, so respect and dignity. So that's acknowledging the unique challenges of the consumer and for us in the paediatric health setting. So having a meeting at 3 o'clock is probably not a good idea, because a lot of families are doing school pickup at that time. So it's being aware of that and not assuming, but asking consumers. Things like having meetings at a regular time so you can plan for that. Scheduled well in advance and documents well in advance. The small things make a big difference. Respect and dignity means engagement with us and not to us. It means asking, not assuming and it also works both ways so at our Family Advisory Council, we're updating our code of conduct to make explicit mention of our guests and presenters and how we interact with them or pose questions. You can imagine, we might have a lot of passion and emotion about particular issues and we need to make sure our advocacy is effective by how we pose our questions and engage in discussions so that it's not intimidating or confrontational, that it's effective and collaborative. Information sharing is another family centre care principle. For example, consumers receiving the same report at the same time as other participants and an effective way of allowing that to happen is using confidentiality and code of

conduct agreements to support that. Inclusion in difficult and challenging conversations is actually a sign of success for our Family Advisory Council. As is when there's ad hoc and spontaneous conversations where executives and leadership staff members come to our meetings and discuss ideas that are not fully explored or fully endorsed, because they're seeking early feedback from us as consumers. Also, when people come to our meetings, but stay after they've done their bit because they want to continue to listen and continue to engage. These are all signs of success about information sharing. Another family centre care principle is collaboration. So that's making sure there's a perception of open and transparent engagement. Decisions not outside of meetings, but decisions and actions and discussions that are documented and it's listening and embracing feedback, no preconceived outcomes or ideas. It means resetting your thinking and be willing to codesign and not just come in at the end with an already designed process. The final family centre care principle that is equally relevant in health care as well as consumer engagement is participation and partnership. For example, consumers having input to agendas and discussion. For our Family Advisory Council, we own our agenda. We collaborate and partner with Children's Health Queensland about the agenda and who's attending, but it is still our agenda and we own it. Again, small things make a big difference. Helping participation can be as simple as a clinician who might be chairing a committee or a working group spending that 5 or 10 minutes before the meeting or after the meeting with your consumer representatives and making sure that they understand the language, the acronyms and seeking their input that might then be drawn out at the next meeting. Participation is also helped by having more than one consumer so that they have support and backup and at CHQ that's a key strategy that is also used. At the Family Advisory Council we actually have a member duty register of who does what, who looks after the issues and action calendar our share point site, our annual report group. It is about getting participation amongst our membership, spreading the load and getting engagement, which helps for succession planning. Participation and partnerships about valuing the skills and abilities of your consumers, we are not helpless parents, but we are here to help you and bring amazing lived experience and often

a lot of professional and other skills that are there to help the health service. Changing that view of who your consumers are is a massive way to make meaningful collaboration. The third point on the slide is smart technology use and using that to help inclusion. This year, our Family Advisory Council has codesigned with the Children's Health Queensland IT department a share point site, which is a website that you can collaborate on. This has been transformational for our Family Advisory Council as it is having a CHQ supported and endorsed document storage and collaboration tool has been so helpful. We use it to store all our documents. It helps us avoid email spam. I'm sure many of you on committees can relate to that. It's our single source of truth and it doesn't matter who is our CHQ secretary support, who is our executive sponsor, who is the cochair of our committee, or who our membership are, we have our history that is maintained and our processes will continue hopefully seamlessly. Video conferencing is another smart technology used that helps support better inclusion and we have a number of regional members who dial into meetings using video conferences. But being smart about technology is also being mindful of when it doesn't work and it's not the best solution. We have a member who prefers teleconferencing, because she has young children. Our meeting's at 5.30 to 8.30 and being on a teleconference rather than a video conference means she's much more able to still participate and hear, but run around, do baths, manage children, multitasking, how to translate feedback in real terms from consumers into change for health care organisations, how to transform. This whole forum is about transforming culture. Well transforming is more than change, it's to change markedly, there's no turning back. Number one, early involvement is key and ideally consumer-led or codesigned. That's when powerful change happens and to do that, you need clear and established channels for wide feedback that you capture in multiple ways, like recruiting consumers in working groups and committees at the planning and issue discussion phases that enable consumer-led design. CHQ is doing that with a central process to engage consumers in their patient safety and quality unit. One of the other challenges is how to systemise using wide feedback. That feedback to patient safety and quality staff, that feedback to social work, those patient surveys or nurse groundings. It is that

early engagement at design phase is a first and priority step, not just what we call a spell check at the end. When you see it happen, you see the lightbulbs go off by leadership and clinicians who say "Why didn't we do this earlier, because we get a far better outcome?" Number two, to transform and make real change you need to make and measure feedback. Reporting on those targets to make them accountable and make them visible, so at Children's Health Queensland there's a number of what we call eye care projects which are innovation, change and redesign excellence projects and they have a target of 50 per cent consumer engagement, for example. So another key thing is rewarding and acknowledging and promoting the people who are doing it well. In fact, the people who are doing consumer engagement well should be the people that do rise through the ranks. You know your organisation is transforming when your CEO talks about family centre care principles and consumer engagement all the time. That message flows down to the executive leadership team and so on. It is also very important to have regular feedback to consumers on how their participation has positively contributed to CHQ service improvement, so closing the loop, tell us that you have heard, you have listened, you have acted and this is what has changed. Oh, and thank you for your help and input. Third point, to transform and make real change, policies and processes have to change and that's about embedding changes by systemising them, in policies and processes that are practical and real, not theoretical. Of course having consumer input into that is very important. It may also be writing new policies or guidelines. Our Family Advisory Council has raised the issue of having a guideline about recruitment. Our committee members have been on recruitment panels for a number of years now, for a number of senior positions at Children's Health Queensland, but having a guideline so that ideally for certain level of leadership roles or consumer basing roles that there's always a consumer on that panel would be a great strategy we're investigating so it's not just reliant on a particularly family centred care, consumer engagement recruitment leader, but it happens because the process is embedded in the system. Finally, to transform and make real change, training is key. That's about supporting staff in a new way of working so that new process for whatever initiative happens regardless of which staff member is

working, which ward you are on, which service you're interacting with, which department. And that means supporting consumers with training, too. For the fact we actually have a buddy system for all our new members, where continuing members support the new members, with support and training. At Children's Health Queensland, the patient safety and quality team have engaged with health consumers for training of both staff and consumers on consumer engagement which has been enormously powerful and helpful. These are some of the ways to translate feedback in real terms into change that are helping Children's Health Queensland transform. Next, Tania will speak to a couple of examples of consumer-led initiatives at CHQ.

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

with their children or their siblings at the bedside and also to be able to eat together, so it's a tremendous initiative and we really thank it's ongoing, but we thank Gary for all his support in doing that. So that's essentially... I know we're running out of time, is the conclusion to our talk today. It is a journey, consumer engagement is a journey. We feel that we're well on the way to that and look forward to coming back potentially next year or the year after to give you an update. Thank you very much.

APPLAUSE

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

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

APPLAUSE

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

APPLAUSE