

Day 1

Partnership Award

Co-presented with Kirstine Sketcher-Baker, Executive Director, Patient Safety and Quality Improvement Service, Clinical Excellence Division

Kirstine Sketcher-Baker: Wow, look at you all. Good morning. I'm delighted to be here today and feel really privileged to be able to present the Inaugural Health Consumers Queensland Consumer Awards. I'm really encouraged by the number of people here in attendance today and am really excited about the potential learnings and networking that can be achieved over the next two days which will lead to further improvement for Queenslanders in the future. Firstly, I just want to say a really big thank you to each of you who are consumers and carers who have participated and contributed in some way to improving health services in Queensland. I'm also really grateful for your dedication, for your passion and for your commitment. Having worked in patient safety over the years, I've met consumers who haven't experienced the best health care has to offer. In fact, in some instances, our health system has really failed them. What often astounds me though is the encourage and often suffice of these consumers to partner with us to ensure the care that is delivered to patients just like them is better. Thank you, in particular, to these consumers and carers. I'm very grateful for your contributions.

Today, I'm here representing the Clinical Excellence Division who's absolutely committed to putting consumers at the centre of all we do. We are very thankful for the role of Health Consumers Queensland and the role that they play in Queensland Health. Clinical Excellence Division in particular benefits from a partnership with Health Consumers Queensland in several ways. Health Consumers Queensland gives strategic advice and training to our staff on how best to engage with consumers. Health consumers also trains and supports consumers to effectively work with our division for better outcomes for consumers. We've also been able to consult with Health Consumers Queensland around particular consumer network issues, so particularly around public reporting, patient information on informed consent, maternity, clinical Senate forums with topics

such as obesity, nursing initiatives and expanded scope of practice for Allied Health, and that's just to mention a few. We also appreciate the ability to work with Health Consumers Queensland around providing intensive support on projects of strategic importance. Some of the current examples include youth Mental Health Services, transvaginal mesh and offender health services.

Clinical Excellence Division is pleased to have been able to sponsor Health Consumers Queensland' annual forum to enable over 30 consumers and carers from outside Brisbane to attend with travel assistance and I also recognise there's a lot of health services that have also funded consumers and carers to attend today. And Clinical Excellence Division has also helped to expand this forum from a 1-day to a 2-day forum to include training and more opportunities for networking. As such, I'm pleased to be here to present the Health Consumers Queensland first Partnership Award. This category recognises how a service and an organisation have meaningfully partnered with health consumers and carers to collaborate to create that leads to better health outcomes and demonstrates the drive, growth and commitment to ongoing partnerships. On behalf of the Clinical Excellence Division and Health Consumers Queensland, I'd like to present the Partnership Award. The winners of the Partnership Award are... drum roll please. Very good! Suzanne Michaels the Change Manager of Caboolture Hospital and Carolyn Wharton, Partner and Consumer. If you could please come and collect your awards. (APPLAUSE).

(APPLAUSE) So without further ado, I'd now like to invite Suzanne and Carolyn to describe the impact of their partnership which has been recognised by this award. Thank you.

Suzanne Michaels: I'm just going to pop the mic down, because I'm very short. A huge thank you to Health Consumers Queensland for this wonderful honour. It's an absolute delight to stand here today not only representing Metro north hospital and health service, but to stand alongside Carolyn who is a phenomenal consumer representative. We're going to share a little bit of our journey with you today to show you the outcome of when a partnership really works. Before we kick off though, I would like to acknowledge the traditional

owners of the land on which we meet and pay respects to Elders past, present and emerging. What we're going to do this morning is I'm going to spend a couple of minutes talking about the system that we have in place that allows our partnerships to get established and to really grow and then we're going to share Carolyn's story, her transition from being a carer to becoming a consumer representative and in sharing that story, we'll be sharing a video, and I'd just like to give you a heads-up that that video does refer to the death of a child. So if that may be particularly affecting to you, you've got a few minutes to I suppose be prepared or to leave the room. Do I have a little clicker? That one? Is that it? Oh, wonderful, thank you.

So, partnerships. I don't know if I could accurately describe how important partnerships are for us in what we do. I genuinely believe it's through genuine collaborative partnerships that the real magic happens. I've seen it with my own eyes over the last few years. Not only magic for consumers who go through that transition from being a patient carer community member to coming on board with us as a consumer representative. But also within our own health system. I've seen our systems change, I've seen our attitudes change, I've seen our profession change, our policies change based on the experience of the people that we work with every day. But what I realise now is that we've made it business as usual. It's up to us as the health service to create that space that's safe, that's secure, that allows those partnerships to happen so well. We're very lucky. We work within Metro north hospital and health service which I understand is the largest health service in the country. Like we honestly couldn't do what we do without their support. We can't have achieved what we have without their ongoing dedication to partnering with our staff, with our community, with our consumers. It's really built into the fabric of our organisation, as you can see.

This is our physical putting People First Strategy here and partnership is a key element of that and that comes from our chief executive Shaun Drummond through our Metro North engagement team who honestly are the heart and soul of consumer engagement within Metro North and they're the ones who are just driving this home all the time through guidance, education and they're the ones who've been able to Metro North and help us to achieve ongoing funding, which helps us to support our consumer engagement activity. So it's really lucky for us that we work within a system that supports us. Locally, we have our focus on caring

together. Now, if anyone was at the forum last year you would have heard me speak very excitedly about Caring Together, because it's my passion. But this has been our commitment locally. We said, we are improving the health of our community by caring together. So we look at that and say, well what are the elements of that? What makes up caring together? For us it means providing safe, accessible person-centred care creating a culture of safety, learning and innovation and being part of a community that provides connected care. We look at every single thing we do and say, are we doing this? Every single activity we're doing, is it going to help us get to this point? If it's not, we stop doing it. What we've created at Caboolture Kilcoy and Woodford, is we have wonderful consumers actively involved throughout our organisation. This is the system I talk about. You have to have a place where consumers can come into, can step into.

We have to be ready to receive them and support them so that they can be as successful as possible. While I'm very, very proud of all the initiatives that we've undertaken in the last few years which I think we could talk for two days on, we've really seen a change throughout the whole system, policies, procedures right down to health information, health literacy activities, actively involved in education. I think it's almost every single day of the week now we have a consumer involved in something in some way and what that does is make sure we have our consumers every day present within the hospital and people have just gotten used to seeing them and everyone throughout the organisation now says to us, "Where's the consumer? Are they involved? Have we invited them? Will they be coming to this meeting? Will they be in this workshop?" While we have amazing consumers, I couldn't speak more highly of all of our wonderful consumers. To Reem a sitting down here and others. Today, we're going to be focusing just on one particular amazing consumer, Carolyn Wharton. So I'm going to show the video now. Just a last comment to you. The video goes for about 15 minutes, and then Carolyn's also going to speak after that and share a little bit more about her journey.

--- Video ---

>>: My husband Bill and I have been together for 23 years. When I met him he came with an adorable little girl Ashleigh, she was 2 at the time.

>>: I was doing rock climbing and Carolyn was a flight attendant working for Ansett. She happened to be on an overnight trip and came along with her sister.

>>: Bill was in the army and was a sniper and did bomb disposals, it was an adventurous match.

>>: In 2003, we were estatic to realise we were having a bub.

>>: I was eight days overdue and it was the night before our planned induced labour I went into natural labour. He placed her on my lap and said "It's a girl!" He asked had we chosen a name yet and I said "Yes, it's Madelyn".

>>: Over the next 6 weeks we went to the paediatrician several times voicing concern. She wasn't feeding well, she wasn't sleeping well. She was crying all the time.

>>: Started to see some involuntary flickering within her eyes. It seemed to go in an arc from left to right and only on certain occasions. We rushed back to the paediatrician and asked him to have a look. Unfortunately, he kept talking to Bill and I and missing when Madhya Lyn did the flickering with her eyes and Bill got his attention by saying, if there is something wrong with our daughter, either you fix her, or I'll fix you.

>>: At the time, we were only getting 40-minute blocks of sleep.

>>: Exactly.

>>: It was just taking its toll on us.

>>: But it worked and within two hours we were in the Royal Brisbane Hospital once again seeing our neurologist. The next few weeks were tough. After many tests and medication trials and trying to establish feeding regimes we were given the most devastating news that any parent would ever want to receive and that was on the future capabilities of our daughter, and her life expectancy.

>>: Madelyn had a few different diagnoses that contributed to her condition.

>>: Severe refractory epilepsy meaning the medication couldn't control her seizures very well.

>>: She had a central cerebral palsy. She was floppy, rather than stiff.

>>: She also had caudal vision.

>>: And nutritional deficiency requiring to be fed through a button through the use of a pump at a low speed.

>>: Most of her feed, some of that related to the form of cerebral palsy that she had. Over time, she also with those nutritional deficiencies, she developed some brittle bones.

>>: Later on developed chronic lung disease because of her condition.

>>: Because of the the aspirations that she had, and over time she also had episodes of neutropenia relating to the medications we had to use for her.

>>: At the time we were given 12 months form adelyn to live. Our lives changed and our new lives began.

>>: We utilised a live within the hospital system for over 12 years and attended many specialist appointments throughout that time. They included endocrinology, neurology, respiratory gastroenterology, the cerebral palsy health clinic.

>>: Dentists.

>>: Yes, the dental clinic as well as many other Allied Health services. Caboolture Hospital became our first port of call with recurring chest infections and pneumonia. We were rewarded with great paediatricians and the final one was

exceptional, Dr Lisa.

>>: The children's ward became a familiar place for us. The staff were almost part of our extended family.

>>: To have a good relationship with the families, it's really important that we understand or at least believe what they're saying. Like you know, sometimes you find when some patients first arrive, sometimes it's hard for them to explain exactly what's going on. But as you get to know the families, you know exactly how to communicate with them. They know how to communicate with us, and you tend to be able to pick up on those little things that they say that either they're not coping, or that they need extra assistance and they seem to be as they get to know us, they find it easier to communicate with us, as well. So, we're all learning together.

>>: Madelelyn's conditions were sometimes challenging, but so was the house system and some of the specialists, but we never gave up. Our goal was to provide the best care we could for our daughter. All of these experiences and diagnosis did not define the beautiful boisterous vibrant princess that was our girl.

>>: Immaculately dressed, hair was always beautifully braided. She had the longest plait, actually.

>>: She was clever, smart and very social.

>>: Very cheeky.

>>: Very cheeky. She enjoyed music and swinging and she would sing duets into whoever she could coerce into singing with her.

>>: Loved animals.

>>: The outfits that she wore were beautifully coordinated and she, you know, was obviously very loved and well looked after.

>>: We treasured every day with our princess.

>>: Yeah, we were very lucky.

>>: At the age of 12, she contracted pneumonia. It was a recurring event due to chronic lung disease. The next 24 hours really didn't go according to plan.

>>: No.

>>: We were informed many hours late into the night that Caboolture was unable to provide the care for our end of life plan, because they didn't have the paediatric equipment available and it looked like they wanted to transfer us to Lady Cilento Hospital. Our shiny light came in the form of the head of ED that night. He was very diligent, kept us informed and he was the first person to come and ask us, as a family, what we wanted for Madelyn. We said we were concerned about the transfer to Lady Cilento Hospital and that we prefer to be at Caboolture in a familiar environment and around the professional, friendly people that we knew.

>>: The staff sort of knew our needs.

>>: And we had organised that plan. We were still not sure what was happening.

>>: Whether we were going or staying or going. No one could give us a clear answer.

>>: And the nurses, everyone was exhausted and frustrated. The nurses were getting really upset for us. They even said "You should be screaming or yelling at us, getting really upset". But I said, we had to remain calm for our princess at this time. I said she needed her parents to know that she was there, she was going to be all right. So the manager from ICU Hamish, came to visit and he spoke with Mosh, heard our story. He offered to take care of Madelyn and she passed away three days later on 9 May at 5:15 pm.

>>: The day after Mother's Day.

>>: Our final conversation in ICU was conducted by the ICU doctor and the social worker and Bill and myself were in a private, small room. Told us that her little body was just too tired.

>>: And she wasn't outputting her carbon monoxide levels.

>>: And that she was dying, so she told us the first thing we had to do was cuddle our girl and hold her tight. I didn't hear anything else past that point. Obviously just clicked into the mother carer mode once more, because our job wasn't over yet and we had to provide the final care for our girl.

>>: And we didn't want to give up at the end, because we put so much into it from day one.

>>: Absolutely.

>>: Several months after Madelyn's passing Bill and I went to the Caboolture Hospital children's ward to thank the staff and nurses for their care and support. It was there Dr Lisa Cane encouraged me to use my experience and knowledge to help other families. But with her support, I joined the Caring Together consumer network at Caboolture.

>>: I actually met Carolyn about three years ago. We were doing surveys with family members and patients for our new paediatric strategy. At that point I'd spoken to 30 families and came into the children's ward at Caboolture and Carolyn was here for a visit and most of the interviews I'd done with people taken 10 minutes and Carolyn got to talking and it was an hour and 15 before I left. You meet with a lot of people and, you know, you talk with patients and families and for a lot of them they haven't had a lot of experience in the health sector or in hospitals. It might be their first or second experience and then you talk to someone who this has been their entire world for 12 years ago I think it was at that point, and they can talk so clearly and succinctly about their experience. They're not saying it's all roses or all terrible. They're just being really factual and like, this

is honestly my experience and this is what's good and this is what hasn't been good and this is what you can change. And I remember, I actually was writing on the iPad and I ended up just stopping. "Let's just talk, I need to hear all of this." It was about a year after that, that I got a call from Dr Lisa Cane and she said "Hey, I've got someone you should talk to", because we had the consumer network up and running then and she said "I've got this great, great person that you should speak with, I think she'd be really great." I said what's her name? She said Carolyn Wharton, and I remembered Carolyn.

>>: So articulate and well-organised and had done such a wonderful job for her daughter, I felt this was something that she would be ideally suited for, would be taking on a consumer advocacy role.

>>: I actually also suggested that Carolyn would be a great consumer, because I just feel that for one, there was a few issues that we had with Madelyn at the end of her passing that we could have done better and so I wanted to make sure that I had a consumer's point of view and because Carolyn was so open and we had worked with her for so long, I just thought she would have been the most appropriate person for us to have.

>>: We had a chat, and I know that first conversation was really interesting, because Carolyn said to me "I don't know what I have to offer. I don't know what I can possibly do here." And I said "All you have to do is be yourself and it will be powerful."

>>: When Carolyn first came to our paediatric service improvement group it was a little bit "what are we allowed to say or not allowed to say? "

>>: She processes information well, and she's somebody who is outside the hospital system in some respects looking in. She's seen the good and the bad of our hospital systems and she's always been very good articulating well where we could potentially improve things.

>>: And you know, since she's actually come on board she's been fantastic. She's very easy to talk to. It makes you feel more humble when you are discussing

patients, because you know also there's the consumer in your meeting and so you also feel as if you're helping the patients, because there's a consumer there that's also listening to what you're doing and making sure you're staying on track with everything.

>>: All of us are patient-focused, but our perception of what that means, sometimes we need that outside voice to help guide us as to what that actually means.

>>: So Carolyn has been really instrumental in putting our orientation video together and she's actually helped us look through some of the pamphlets that we give out to parents to make sure that they are appropriate and she's also as we walk into our unit, she's actually helped to resign our entrance just to make sure that it's more consumer-friendly, so people know exactly how to get into our unit. So she's been a great help.

>>: Carolyn's actually involved in our medical education each year. Right at the beginning of the year we do doctor orientation, three sessions over three weeks and we've used Carolyn's actual experiences and created an hour-long session on patient and family-centred care. We have a particular session on clinical handover, which is based on one of the experiences that Carolyn had and she's part of that- we do a simulation and she's part of that and then our medical officers are able to ask her questions and pull apart what happened. Whether it worked, whether it didn't and what they would do differently.

>>: So I enjoy working with Carolyn. I just think that she is fantastic. She's always thinking about the patients and the families and how- because she's got that experience, she knows exactly what they're going through and so I think it's a great asset for our unit to have someone that is also so passionate, but also keeps us in line and because we've known her for so long, we have this great communication so I feel that I would be able to tell her anything and then I would hope that she would be able to do the same for me.

>>: It's been very easy and I think you've got a woman here who is very, very suited to that role and I think that's part of it, is that she makes it easy to work with

her and she's now part of our team and I think that's where we've gained, her loss has actually been our gain.

>>: This journey has empowered me. It's given me somewhere to channel my injuries and my passions, but most of all, it's created a legacy for my princess, Madelyn. (APPLAUSE).

--- Video ends ---

Suzanne Michaels: Thank you for allowing us to share that with you. We only just did it very recently, but I think it beautifully captures the journey that Carolyn's been on, but she's also just now going to share a few more words about her experience moving from carer to consumer.

Carolyn Wharton: Thank you. The journey from carer to consumer is very rewarding. It's emotional, it's personal, it's exciting, but it definitely needs support. My husband Bill and I were caring 24 hours a day for over 12 years for our gorgeous princess and then everything changed. Our routine was so engrained in our daily lives we were still instinctively jumping up to prepare feeds and medications for weeks after Madelyn was no longer with us. The grieving process is very individual and it's difficult to know when you're ready to tackle life and the real world once more. So many thoughts run through your mind. For me, it was the mixture of "what happens next? What do I do now? I'm so sad all the time, and I have all this time. Do I need to think about work yet? Goodness, I haven't been in the real world, in the workforce for 15 years, where do I start? Do I need training or to do a refresher course? Actually, I don't want to think about it at the moment." So our GP gave us great advice. He said "Hold everything off for 6 months if you can. Don't rush into anything and just have a break." I felt like I just needed that time. Time to just exist, to float along for a while and time to find my new normal. As mentioned in the video, it was Madelyn's paediatrician Dr Lisa Cane and the nurse unit manager of the children's ward Michelle who asked if I would share my knowledge and experience to help others through the consumer network. Lisa and Michelle and our family had a very good rapport over the years and established a strong, trusting partnership. The trust was the foundation I needed at that point in time to look further into her suggestion of the consumer network. Her

suggestion to join the network was an uplifting surprise. I had a positive option or direction to consider where I could pay it forward, share my knowledge and help others. I felt this could help me in my healing process and it was in an environment that I was familiar with. A bit of a comfort zone, because I've been utilising the hospital and the health system for so long. I also felt a positive reinforcement that what I did as a carer and how I conducted myself as Madelyn's advocate must have been good. We must have done things well if we've been asked to help.

We know our family worked incredibly hard to do everything possible to give our princess the best care we could and utilise every opportunity available to us. But to be asked back as a consumer and invited to join the paediatric service improvement group, to work with staff and make improvements felt like an acknowledgement of sorts. When I joined the consumer network, it had been running for about six months. I met with Suzanne and we spoke about the group. I saw it was a well-organised committee with great opportunities and the possibility for consumer engagement seemed endless. My impressions of the first committee meeting that I attended was the group was well-structured, efficient and everyone seemed to have roles to play. There was so much scope on offer, I was a little bit overwhelmed, thinking "Where do I begin and how can I contribute?" Suzanne, who is incredibly attentive and supportive and has a knack of simply ever so gently immersing you into the consumer involvement, she started by asking questions like- do I have a particular area of interest within the hospital?

And of course my response, well I know paediatrics, the emergency department and outpatients pretty well. And she said "That's great, but what about you? Are you comfortable to work within those areas?" Obviously knowing about my personal journey, and taking that into consideration, "Are there any areas you wish to avoid?" My response was "I'm comfortable in all those environments, because it's what I know from my personal experience and I have an understanding of how they work." So after reassuring me that I could do as little or as much as I like within the network, we began from there. Suzanne had spoken with members of the paedics and ED improvement service groups to the directors, the management prior to my first meeting. She buddied up with me and accompanied me to the first one or two meetings until I was comfortable to go it alone. Why this collaboration worked is because the incredible support and guidance from Suzanne and Rachel

Latimore who followed Suzanne as the consumer engagement manager and all the management and the leadership staff. From the very start, they welcomed me to the meeting. The directors actually set the example for all other staff and included me in the discussion. Some staff were a little wary of my presence initially, but began to relax once they realised I was not there to judge or point the finger. It wasn't long before the walls and barriers came down and partnerships developed. It soon became obvious that we all wanted to create change that leads to better health outcomes and that we were caring together, to improve the care and the health journey for patients, carers and their families.

The relationships with clinicians has changed for me. I didn't have any fears or worries about this prior to joining, but I soon came to realise it was going to be a different relationship. I no longer feel like I'm on an individual family's journey. It has become much larger than me, and is now a combined journey, a community journey, with its local hospitals and the health service. We all want better outcomes for the patients and their families, so we've united together. As a consumer, I look at things more holistically. I now see the challenges, the restrictions and the limitations that staff are working with. As a carer, I was focused entirely on my princess and my family. Madelyn was number one. Now, as a consumer, I'm part of the team who delivers that care. I can see the processes and their concerns and I can share in the positives and the wins and together we strive to reduce the negatives and the losses. While being a part of this team, I've experienced some moments of clarity, which I'll share with you. These moments verify to me that we are caring together. I was invited to attend the ED morbidity and mortality meetings.

In these meetings, staff look intensely at the detailed case studies on certain patients who have passed away. These meetings are run by ED staff for ED staff and related services as a non-blame, open discussion, safe learning hub. I was really impressed when I attended this meeting. It showed me a whole other side to the staff and to the length that they go in order to improve the care they give to the people. They dissect every bit of evidence, all the signs on presentation of their patients as well as all the treatments given. They are always asking "Could we have recognised anything sooner? Could we have done something different? Would that have changed this outcome in any way?" That definitely was a moment for me.

Another was with new doctor orientation. I've been presenting at new doctor orientation for the last two years and two weeks after one of the presentations earlier this year I was approached in the corridor from one of the new doctors coming from the children's ward. She rushed up to me and thanked me for my orientation talk and for sharing with her the details of our consumer engagement and partnerships within the hospital.

She then went on to talk about our consumer feedback working group and our consumer liaison officer, Kim. This new doctor had a different scenario with her mother and her child on the ward. The family had terrible experiences in the past at other hospitals and they were concerned things were not going to plan again. So this doctor utilised the information I had presented to her at orientation. She contacted the CLO, resolved everything while the family was still in the hospital and arranged for follow-up care for the future. The outcome was very positive for everyone involved. The doctor was so impressed that she had the tools and the resources available to resolve these issues and improve a patient's journey on the spot and she was very grateful to me that she'd learnt about them through my orientation speech. It was a win-win situation. I turned to Rachel our consumer engagement officer at the time who was walking along with me and said "That is why I do this, the positive outcome makes all the difference." The final moment I'll share with you is when I was asked by one of our paediatricians at Caboolture if I would have a conversation with him about end of life care.

He mentioned he had a family with a child, who would need to access end of life care in the near future and he asked if I'd be able to talk with him about my personal experience in this area. We spoke about the plans we had in place, what worked, what we could have done or would have done differently and what else does he need to remember and consider? He just wanted to make sure he had everything covered. I could see he was invested in this family. This was a raw, open conversation that I agreed to have, because it could make a difference and help another family. So, the future. Suzanne always asks me, what's the future? It's the most difficult question for me. I can never give Suzanne a straight answer for I'm not really sure. All I know is that we were a lifeline for our beautiful princess for a long time. And that was an amazing journey. I got through the video... dear. It had incredible highs and many challenges, and it's really difficult to understand the

elements of this journey, of being a parent to an exceptional little girl unless you have lived it. So for the first time in many years I personally have options for my future. I can work with a great partner or team and assist and help others master their skills to improve someone else's health care journey, and I really enjoy doing this and when I need to, I can simply pause and take a moment to remember the incredible journey that brought me here. Thank you. (APPLAUSE)

>>: We did it. (APPLAUSE)