

Hear me out! The importance of patient stories.

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Robert 'Bob' Rix, Consumer Representative

Breakout Room 3: 15/06, 14.00-14.30

I would like now to introduce Lauren Northey and her able assistant ... their presentation is "hear me out" the importance of patient stories which is what we are here about in total today, about community engagement. Without further delay, Lauren, if you would like to take the podium. Lauren is with the Sunshine Coast hospital health service and is their acting principal engagement officer. Bob is a consumer representative. Thank you.

Lauren: Hi. All right. Hello, my name is Lauren. And I'm a nurse from the Sunshine Coast. And I'm here to chat about the importance of patient stories. This is a relatively short presentation. I will try to keep it light. There was a small project that we ran on the Sunshine Coast a couple of months ago and probably the most important part about this is who I call my celebrity consumer Robert. I might pass over to you, Bob to get us started.

Bob: Okay. You all know me by now, my name is Bob. My story starts about six years ago of the I was sitting down watching TV and suddenly these firsts fell on top of my legs, within an hour they increased to the size of a 50c piece. I decided because it's Saturday, I had missed the doctors and I would wait until Monday, it got worse. I went to the doctor and I told me he doesn't know what it was. But they treated me and bandaged them and for six months I put up with this and it wasn't working and they finally decided to tell me and -- that I needed to see somebody who knows more about the job. They sent me to a specialist at Nambour. I had some wonderful nurses there that looked after me, got my legs nearly better and then I had a set back again. They sent me over to the new hospital and I met two fantastic nurses. And one of them is here with us right there. You will see shortly the photos of when I was transferred from Nambour to this hospital, to what they are

now. And when they showed me the photos I nearly cried. Because when it first started, all they told me was we might have to cut the leg off. Well, I no longer have to have that. Very shortly, I will get up and I will dance with those two nurses.

Because they have done a wonderful job.

Lauren: Thank you, Bob. This is -- you will see why Bob is the most important part of this whole project and feel free to interrupt me at my time because people want to hear from you and not me. This is the project and how it came about. So at the start my history is as a vascular nurse. We have patients with a lot of chronic wounds. We started to see patients coming back to hospital, the same wound would say breakdown in the community and we poke with them each time about what was bringing them in. By and large we were getting responses that they were being treated by different clinicians in the community, GPs or mobile nurses or nurses -- and there wasn't enough support and education in the community for them to deal with really chronic wounds. So, where are we? So that was probably the first part, so finding out information about what was bringing people back into hospital. The second bit was finding a consumer that would tell a story that was willing and open to be recorded for that portion of things and I will pass to Bob in a second about how that felt. But that was a challenging part, because we needed -- we knew we were going to share the story widely. We were planning a large education day that we wanted to repeat a few times in a row. It's not easy to be vulnerable when you have been through such a journey. We have been lucky Bob has been here today.

So we filmed Robert's story as part of the project. We did that at the hospital on a visit he came in to have his wounds dressed. Then we planned this education day for the clinicians to come in and I will show you a photo of that as well. The first section was talking to consumers. Like I said, what brought them into hospital, who was looking after their wounds and then how can we improve things. That was really what got the ball rolling.

And here we are, finding the right consumer. So talk to everyone about how you felt when we approached you. When you were selected for this process.

Bob: Well, I thought you were joking with me at first. Why would anybody want to see and hear what happened to me? But then when I

looked at it, I think I should have the right to tell my story. And what you have done for me and the treatment I have received from so many different doctors and nurses and finally found one crew that knew what they were doing and got me on the right track now. So that was great.

Lauren: All right. I would love to show you Robert's video now. It goes for about five minutes and there are pictures of his wounds throughout. And a fantastic outcome at the end.

Video shown:

Lauren: To be honest, we probably can't, Bob, because the sound isn't working.

Bob: Have I just turned it down?

Speaker: No.

Lauren: How was your quality of life affected, Bob?

Speaker: You broke it.

Bob: Oh, I don't have to change hospitals again, do I?

Lauren: Well, what were things you weren't able to do when your wounds were at your worst?

Bob: Once I got better I like to play with my nephews or nieces, I have not been able to do that for over six years.

Lauren: What was it like having your wounds dressed when they were at their worst?

Bob: They were very sore and painful. I was taking up to 20 pain killers a day. I thought I was going to be addicted to them if something wasn't done. But it didn't turn out thank goodness that way. And as time went on, things got better and as you will see in these photos, great. And

they are going to get better too. Which is fantastic. I can't praise the nurses that have done this to my legs. There is no words. I can't put into words how good they are. One of those nurses son's -- he -- if he turns out only one fifth as good as his mother then we have great nurses here on the coast.

So it's a pity we didn't see the ones before this. These are only the photos taken from the Sunshine Coast. I would like you to have seen the ones from the Nambour hospital.

God he's a good looking fella.

Lauren: All right. When did things start getting better?

Bob: Well, they started turning around about three weeks after I arrived at the new hospital. They changed the bandage set-up. And from then on everything has gone up hill and it's coming great.

Lauren: Tell me how you felt when they decided to change the bandages. That would have been something that was happening before and maybe not working?

Bob: I thought it was a waste of time. I thought if it comes down to it I was going to get my legs removed. All right? I persevered with it. Those nurses, they helped me out. Because I couldn't understand half the time what they were talking about. I'm only an old fart. The language doctors use goes straight over my head. Talk to me in straight English and I understand it well, they did. With their help and the way ... I feel great here. I look forward to coming up there. That's a stupid thing to say, who looks forward to going to hospital? But I do because they have turned out to be just like my family now. They all know me. I walk through the front door and even volunteers know me. If I walk down the main street of Caloundra and somebody sang out my name I would be hiding because I wouldn't know if they would come and bash me. Here you walk into hospital and you are right there.

Lauren: I wanted to touch on that, about the change in the dressing regime. Because a very wise woman once told me when you have a patient with a chronic wound in particular in the community and you are meeting them the first time the most therapeutic part of the meeting is

developing trust... because these people have already been on such a long journey. This is what Michelle said. You can tell ... they have already been through so much and they don't want to meet a new person that has a new idea when this has been happening for years. I just thought it was very powerful, that's what I took away from your talk, Michelle. I say to Bob he has such a partnership with the wound care nurses. That's part of the reason he has had such a good outcome. I know he sings their praises and I don't doubt they do an amazing job but he has been part of that as well and that deserves praise as well.

Bob: I was only thinking the other day, I have been having these wounds done now for six years. And in that six years I have met a lot of nurses. I tell you what, the amount of times Michelle and Henrietta and that has done my legs, I don't think I've done a bad job in training them.

Lauren: I love that. Because I have had the video, they can hold you to that. This is what the actual education day looks like. After we filmed the story and looked at what we were going to include in the content to share our knowledge with community clinicians, this was the day we came up with the demographics. An interesting early winning point for me, we took this to our local consumer publication group for feedback. I naively having just joined the engagement team wagon thought it would be great to get some feedback on it and very soon learnt this is not co-design at all; this is already being done and you are taking it to consumers for their ideas. They very swiftly explained to me that is not how things work but that's a good learning point. This is what the actual education day looked like. We had 60 people turn up on a Saturday. We didn't charge any attendees or any of the trainers to come for the day which is a big win. But amazing all of these people turned up on the day or the weekend and we didn't have a single person not attend, which I thought was nothing short of incredible. We had surgeons coming to talk to the team, nurses and occupational therapists and in that group, that was the same with the attendees that did come. So that was brilliant. In the afternoon we had some practical workshops on managing complex wounds and applying very impressive compression dressings which Robert is showcasing now down the front. So what was the feedback from the day? We did a little bit of surveying -- because it was the first time we had run such an event we wanted to know how we were going. Up the top is a word cloud of text feedback people gave us. Down the bottom was a question about Robert's story. Because I -- I really wanted to know I was on the right

track. Evidently I was because the two neutral people only said that they needed the whole day to be longer, so they would cut things out, make this shorter so they could fit in more time.

Bob: Pay me more and I'll do it for them.

Lauren: All right. This is the last slide. It's about what did we learn from it. Like I said I'm very junior in the engagement space. But this activity taught me so much about the power of the patient story. When we got on board with the idea of including a consumer as part of this day, and I was telling the other clinicians about it and trying to arrange speakers, that was the only thing they needed to hear before they were on board. And I guess I was naive on that front as well, thinking that people would be so excited about that. But the enthusiasm that was generated and the traction we got and the amount of people that wanted to be there because they knew we would include information relevant to what they do every day it was so impressive. I was just amazed. And I guess it made me realise that long term the benefit of that video, while the video is brilliant I think because I edited it and it took me forever -- the better thing we can do and are hoping to do next time is have Bob come for the day and speak and be present of the that's probably the second thing I learnt. While the story is impactful, having the person to tell their story is even better. As evidenced by the fact you just did that. We can always just play images and have you talk.

Bob: That's all right. I'm happy to talk to anybody.

Lauren: Finish off by telling us how you have found all of this, this whirlwind.

Bob: Well, I think it's great. Now I have someone's attention ... I'm starting to like it. But I'm just hoping it will come to an end. And when it does come to an end it means these are my legs and I'm up walking again. And then I will be happy. Yes, I will buy you a lunch the day I walk out of surgery.

Brilliant. Thank you.

Lauren: You had 10 minutes more.

Bob: I liked to keep it brief. It's the afternoon.

Lauren: Thank you very much. Can I look at your legs? Trust me, I'm not a doctor. They are beautiful, aren't they?

Bob: You wait till you see them without the bandages.

Lauren: I think I would wish for legs like that. A most interesting story.

Audience Member: So you need to be able to push in multiple directions. If that push comes from consumers that's important. You really need that bottom up push as well. so we must educate consumers. Is it okay to ask and advocate ...

Lauren: And also provide that feedback to the powers that be. Absolutely. With the consumer consultative committee, going on that journey and so many people are aware, they have a voice. It certainly helps in accreditation which we went through last year and also the planetary process to be able to talk about it. It's very much helped...

Lauren: Has anybody heard of the choosing wisely initiative? That's a new one that has been adopted by at least 26 different health services across the country. It's about empowering the consumer to question their GP or specialist, do I need this? Is there an alternative? What happens if I don't have it? Hopefully you will hear more about that because the medical association has ... they have bought into the concept.

Audience Member: I agree. At the moment I'm on secondment working in a division in allied health. I hadn't heard of the choosing wisely initial until that point in time. I actually refer to it in one of the state-wide guidelines that I have been working on while I have been there. Hopefully we will hear more about these things.

Audience Member: Hi, I'm Jacqui, I'm a consumer. I just wanted to sort of make a point especially around mental and with mothers and their children. I was involved with Al-Anon for many years and I spoke to a

lady talking about her sons and she was talking about how her son had been placed in a job in another town and Centrelink paid for him to get there but he mucked it all up the night before by getting into a fight with one of the other workers and he was stuck out west and no way to get home and centre link wouldn't pay for him to come back home again so she had to use her electricity bill and photo for that travel -- for him to travel out with her other son, her other son to pick him up. I said Oh yes and how old is your son. She said 40. You know, just like you go, "What?" You need to let go of the apron strings. It's like you are made to be this knew rottic person who can't let go of the a were on strings because you are trying to support a family member who is not in a position to make good decisions for themselves. Because of their mental health or it might even be because they are ill or with another organ of their body. It's just the stigma that is attached to care providers or -- from a mother's perspective, that you need to let go and let that person have their own journey. But when you want to support a family member, you don't want to be ridiculed or made to think that you are sticking your nose anywhere it's not wanted. But we if you want to change the world, go home and love your family. If you see a family member struggling, stand up for them and let that be the norm instead of -- people sleeping under bridges. Everybody has a family. Every one of those people has a mother or father or brother or sister, that they have been pushed away and that person has lost their support network. So you are right, it's back to -- for that to be encouraged, to give them a buddy.

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