

## **Consumer Conversation: What does safety in healthcare mean to you?**

4 November 2020

- Safety is at the very foundation of healthcare, but how often do we think about what safe care looks and feels like to us?
- How often do we consider what the healthcare system does to keep us safe?
- Have you ever felt uncomfortable or unsafe when receiving healthcare?
- Do you feel you can speak up if you do start to feel unsafe?

This was Health Consumers Queensland's 21<sup>st</sup> conversation with consumers and carers since March 2020. It was clear from the conversation that although consumers assume they are getting care in a safe system and many of the safety nets are invisible to us, consumers can clearly identify and describe what unsafe care (and unsafe environment) feels like to them. All of the 28 people who attended brought their passion and their experience to this conversation, everyone had something to say. Safety is one of the tenets of the Australian Charter for Healthcare Rights.

We heard clearly how much safety matters to everyone who accesses health care. Yet what it looks, feels, sounds and tastes like for each of us is unique - and extends far beyond a single perspective of clinical safety. What feels safe for one person, may not feel safe another.

Consumers and carers were joined by Dr Jillann Farmer, the Deputy Director-General of Clinical Excellence Queensland who responded to their feedback and affirmed the value to Queensland Health of listening to consumers' diversity of perspective saying, "We need your partnership to ensure vulnerable people can be heard and protected. We will get the best answers when we get diversity in opinion."

### **Overall summary**

Regardless of a person's level of privilege, health literacy or familiarity with the public health care system as an experienced consumer representative, patient, carer or staff member, there is a shared sense of apprehension and disempowerment in speaking up about care that feels unsafe for fear that care could be compromised for oneself or loved ones.

This sense of apprehension and disempowerment – of "being blocked" - is particularly exacerbated if:

- you identify as LGBTIQ
- you have a disability
- you are from a culturally or linguistically diverse background and no one speaks your language

- you are a consumer, carer or junior staff member challenging the care or decisions of a senior clinician or supervisor
- you are challenging the care of a staff member or team within a small community or from whom you regularly receive care
- you are a carer having to point out a problem with the care of a loved one who you have to leave at the end of visiting hours
- you have to invoke Ryan's Rule or another patient safety protocol or review process
- you feel very unwell, are in severe pain, are elderly or vulnerable e.g. you have neuro-cognitive issues and cannot speak for yourself
- you are a health advocate or known to be part of Health Consumers Queensland's consumer network
- the system is fragmented
- you are met with fear and defensiveness from staff members.

## **Key safety themes for consumers**

*What are the consequences if I speak up about my care or a loved one's care?*

A number of consumers expressed their apprehension of speaking up if feeling unsafe about the services they are receiving because of their concerns that the care will be compromised, they are relying on these people for care or "the relationship will become worse".

One consumer said, "I've actually discharged my stroke survivor partner. After I did attempt to call a Ryan's Rule no one came near us for a few days. I felt really unsafe leaving him. Now I really dread going back to the health service." In her words, her partner had been "put in the 'too hard' basket" and cautioned that as Queensland's population continues to age, it will be more important to be able to address the communication needs of neuro-cognitively impaired patients.

*What are the consequences if clinicians are disempowered?*

A consumer described the vulnerable position that both she and a doctor who has a disability were placed in when he had to do a procedure which was difficult for him given the particular type of disability he had. She said, "Unfortunately his disability affected my treatment and I hung in there with the pain because it wasn't his fault he had been put in the position when somehow people should have protected him. I said 'thanks very much for helping me.' I understood how hard it must be having a disability and put in a position where you have to tell a patient you have a disability and he feels embarrassed and you end up being in pain."

In responding to this experience and the role of the consumer in playing an unanticipated role as a clinician advocate, Dr Jillann Farmer said that Australia has been slow to enact treaties to fully express the intent contained in the Convention of the Rights of People with Disability. She said that doctors who have disabilities are an important part of the diversity equation and need to be supported to work safely and preserve their medical careers without compromising patient safety and quality of care.

### *What if I'm gay?*

Despite declaring to value diversity, it is time for the public health system to address the disadvantage that many diverse and vulnerable people face in accessing care safely which can impact on their sense of self-empowerment and advocacy.

A consumer who identified as being LGBTIQ said he felt 'physically' safe most of the time within health care settings. However, "I don't feel psychologically safe a lot of the time because I'm gay. I worry about the responses - not so much the nurses - but some of the clinicians, cleaners, food people - people who come and go all day. The other major problem is that I don't feel safe around some of the other patients. If I'm a white gay man what does it feel like for a trans woman or someone doesn't identify as binary?"

This concern was echoed by another consumer who cited the experience of "a young trans person in a mental health unit being traumatised by misgendering and misunderstanding."

The first consumer, who is an experienced consumer representative had gone on to share information about trans and non-binary training and policies which are being or have been introduced by Hospitals and Health Services in south-east Queensland. The second consumer acknowledged these developments but asked: "How long will that take to trickle down to the staff where it matters?"

### *What if I don't understand?*

It is very hard to feel safe, respected and heard when English is not your first language in our health system. One consumer shared: "I had an operation 20 years ago. I felt very safe because the doctor could speak Chinese and I clearly understood what was happening. They always discussed with me about the next step. 10 years ago I had another operation. At that time I felt very nervous because the nurse didn't talk to me and didn't smile. I felt it was very serious. People communicated with me without feelings. I wanted to ask questions but I didn't know who I could ask. How could it change so dramatically?"

Even when there is not a language barrier, the clarity of information and the way it is communicated has led one consumer to take the 'micro-managing' approach to counteract feelings of insecurity. Although he describes himself as having 'high health literacy', he said he feels unsafe "when the information is vague, confusing, contradictory and/or seems to be not wanting to give information clearly and with full risks and benefits." He is always keen to ensure that "the information and advice that clinicians give (in a surgery context) is clear, concise and is, hopefully, recorded in some way, at least written down in notes made by myself and the family." He added, "I think there is a lack of written information given by clinicians when discussing with patients the next options for either elective or emergency surgery. Often it is just told at the bedside and there is a mis-placed expectation that patients there lying in the bed will just be able to capably understand."

A consumer highlighted the disadvantage that people who are very unwell face when being given information or updates on their condition or treatment. "Bedside consults often go

over the heads of very unwell patients. It's essential they have a health literate family member or advocate with them plus a cross section of health professionals. Being told by a sole doctor that your surgery and treatment has not worked when you are physically and emotionally unwell - without any supporters present - is soul-destroying. Trying to request a family case conference is almost impossible - professional did not see the need and you are too unwell to force the issue."

*What can I do when my concerns are met with defensiveness or even aggression or it becomes a box-ticking exercise?*

According to an experienced consumer representative it is not unusual for staff members to respond with defensiveness and this is what causes her to feel unsafe. She said, "It is when I politely express a concern and I get shut down. They start blaming me for having a problem in the first place. They are lovely people. They mean well and work too hard and are overstretched but they immediately move to a defensiveness. This is where a lot of health staff are. They can't or don't want to handle it."

Another experienced consumer representative shared how patient comments at his HHS were treated as complaints. "Written complaints were responded to, but there was no follow up to see if the answer was satisfactory." This inability to openly discuss concerns spilled over into the way the Patient Safety and Quality committee he attended conducted their meetings as well noting: "We were not allowed to have any discussion on issues where service was clearly at fault, [the] barrier was 'confidential to patient'."

Yet another experienced consumer representative had also experienced this approach at his HHS, commenting, "We get asked to leave when the tough stuff is to be discussed. That said, I think [] HHS does it pretty well and I feel valued on the Committee."

Another consumer who has frequently accessed health care over the past 30 years agreed that health care workers are overstretched. He said, "I study people in hospital waiting rooms and in bed, I'd hate to be a nurse today. There used to be plenty of time for care, for getting to know me as a patient - about my story. The staff are doing more and more work. I'm always saying, 'Make sure healthcare workers get help. Don't keep giving them stuff because that reflects on the patients.'

*Where do we stand?*

A consumer who previously worked as a mediator said that one of the issues with managing complaints was to do with the power imbalance perceived or otherwise between the two. Another consumer observed that there is a difference between what safety means from the top down or from the patient perspective. The first consumer then went on to say, "I really think the medical profession is in flux - patient, client, consumer - they don't know how to treat us and we don't know where we are."

## **Consumer recommendations: addressing people's safety needs**

The public health system is relationship-based and the group explored how consumers and staff can move beyond the fear and lack of trust and work together to improve the experience of accessing health care, feel safe and be empowered.

*Change the culture of the 'blame' environment. Train staff to be effective mediators and support a 'curious and compassionate' approach*

Individual health professionals are well-intentioned but it isn't enough because the system is not currently enabling health professionals to respond to concerns from a curious and compassionate standpoint.

A consumer asked, "How do we teach health practitioners to be good mediators to resolve and defuse situations to put us at ease?"

Another suggested, "We need to actually have that conversation with staff about why it's painful [when consumers say something feels unsafe] – we don't want to make formal complaints. We want to have a conversation to improve things so it doesn't happen to someone else."

This recommendation was supported by another consumer who has sat on Patient Safety and Quality Committees and noted that current complaints procedures are flawed: "Everyone gives feedback within 5-7 days - everyone looks good but 6-9 months later complaints not dealt with - what have you told the families?" She said that what people really want to know is: "If I come back next time, is it going to have improved?"

Dr Jillann Farmer acknowledged that the seven day acknowledgment system has become more about meeting the target rather than engaging with curiosity. She also acknowledged that challenging the current approach is one of the more challenging issues to solve but stated: "it starts with the advocacy today."

She went on to say: "We tend to behave as if a single event is an aberrant event without looking at the circumstances around that person - what created that vulnerability - then engaging with curiosity and compassion to compensate for whatever created that vulnerability... Our response has to be one of curiosity: How is it that in spite of our genuine desire to do good, we sometimes do harm?"

A consumer responded that this 'curious and compassionate' approach is key but wondered how this could be adopted by staff members.

Dr Jillann Farmer agreed that the ability to listen effectively can be hijacked when in defensive mode. She said, "We need to get that balance right between accountability versus a supportive and curious environment. Then people are more capable of listening and engaging."

Dr Farmer added that Queensland Health has been training junior clinical staff to challenge supervisors in a way that doesn't cause offence and suggested that some of these training

tools could be made more widely available to ensure clinicians are better and more resilient to receiving feedback.

She also recalled an open disclosure programme she'd worked on which focused on families who had experienced a health-related death. She reflected on one of the central challenges for participants: is an apology an admission of liability and described the concern that engaging in a conversation would make it worse for everyone. However, at its core there was a sense that this death would have meaning. "We would treat it with respect and learn from it."

#### *Increase health literacy amongst consumers and carers*

A significant level of health literacy was cited as one of the tools for increasing people's confidence to have the difficult conversations by a number of consumers. One remarked, "Having health literacy has been a real tool to be able to make me feel comfortable and say, 'Well, actually, this is not OK. It shouldn't be like this.' It comes from empowering the patient."

#### *Focus on communicating effectively*

A number of consumers and carers highlighted a vital need to address the quality of communications between health staff, patients and families. "Regular communication is relatively simple and can easily alleviate fears and stress." maintained one consumer whilst another suggested that health staff need to value the time it takes to communicate – or "have five minutes to stand at the foot of the bed."

Dr Jillann Farmer referred to the language barriers experienced by many culturally and linguistically diverse people and said that Queensland Health is not currently doing enough to signal that staff with multiple language skills are particularly valuable despite the impact of these barriers on safety and quality of care. She believes that a multiplicity of cultural and language reference points create a diversity of approach, especially in regard to problem solving, which could be a great strength for the system.

#### *Share information not data*

A consumer representative who sits on a number of committees suggested that the way safety data was compiled into banks of incidents and events – sometimes 350 pages long – was too binary and focused on solving critical incidents rather than giving a real feeling about levels 2,3 and 4 and replicating what people were doing well across a hospital and health service.

Dr Jillann Farmer said that it was helpful to distinguish between data and information and that the Tier 2 committee she is chairing is setting up a review of safety and quality reporting to drive more useful discussions. "I sometimes feel the obsession with production of large volumes of data almost a placebo to feel we are doing something without having those conversations which are more painful and more bruising but ultimately lead us to a better place."

*Value consumers as equal partners in our care*

“It's about us being equal partners in our care - when you feel included and belonging and receive information in an easily digestible way, there is mutual trust.”