

Magic bullet or bitter pill: Understanding what the COVID-19 vaccine and its rollout mean if you have a complex health condition or disability

Health Consumers Queensland: online Consumer Conversation

Who: 41 consumers were joined by Queensland Health representatives Dr Liz Kenny (Chair, Queensland Clinical Network Executive Chairs), Dr Carl de Wet (GP Clinical Lead, Healthcare Improvement Unit and Primary Care Clinical Lead, State Health Emergency Coordination Centre) and Robert Hoge (Executive Director, Strategic Communications Branch).

When: Monday 22 March 2021, 12.30-1.45pm

Background to the conversation: Many people in Queensland remain in isolation or are still living with significant restrictions because of a health condition or disability one year on from the declaration of the COVID-19 public health emergency.

For some, the COVID-19 vaccine could be the magic bullet which finally enables this particular group of people to move beyond the confines of their home and pick up the threads of their everyday lives. For others, the lack of tailored information or advice about the vaccine in relation to a specific condition, disability or health concern is causing them to wonder if the potential risks could outweigh any benefits.

Key reflections and action points

Most of the consumers who attended this Consumer Conversation, living with chronic and in some cases multiple conditions, mean they are in category 1B, which is rolling out now. For this reason they experience a real sense of urgency for them to get the information they need about the vaccine: is it safe for them (and their specific circumstances), how and who they can have this safety conversation with, and when they will be vaccinated. Their key points were:

- [This is] “an extremely important conversation”
- Conversations [with trusted health professionals] matter more than communications
- Communicating uncertainty with confidence - it’s ok not to have all the answers but avoid cliches
- The importance of transparency around decision-making on vaccine group eligibility
- Patience? But aren’t we in a hurry?
- The media is louder than Queensland Health
- Are consumers really on their own [in navigating if and when they should have the vaccine]?
- Making an appointment online is too difficult
- Helping consumers understand information to know what’s important
- What is the incentive for people with disabilities to have the vaccine?

“An extremely important conversation”

There was a significant turn out for this particular conversation with consumers and there were many new faces who have not attended previous conversations. At times, the tone was urgent and there was a sense that people were determined to grasp the opportunity to actually speak with trusted health professionals about their particular concerns – such is their level of concern about what this vaccine means for themselves and their loved ones, especially if they have underlying medical conditions.

Above all, this Consumer Conversation was a powerful example of meaningful engagement. The openness and transparency with which the consumers and panellists alike shared their concerns and perspectives with Queensland Health representatives was met with mutual expressions of respect and appreciation. It was a lesson in the success of this vaccination programme being ultimately not about trusting the vaccine but trusting each other.

When conversations matter more than communications

The current government or departmental guidance on the vaccine is not enough for this group of consumers. Generic, generalist, one-size-fits-all health information does not work for this particular cohort (those living with chronic conditions and in vulnerable populations such as First Nations)). Moreover, these consumers already know they probably will not find the individualised answers they are seeking from the Queensland Health website or by calling 13 Health or the Coronavirus hotline. For some of these consumers even their GP or specialist doctor cannot answer some of their questions, because their condition or disability is complex and vaccine criteria is complex. “I phoned 1800 020 080 [the Coronavirus hotline]; it was like ringing Telstra.”

Although it was made clear that this event was not a Q&A forum, the number and highly specific nature of many of the attendees’ questions about conditions or previous adverse reactions and the level of clinical or personal detail they were willing to share on a public forum in order to get the answers they seek, suggests that people are in urgent need of conversations – rather than communications – with highly experienced professionals they can trust in order to make informed decisions about having the vaccine or not “*[I] want specialist rather than GP backing.*”

Communicating uncertainty with confidence - it’s ok not to have all the answers but avoid cliches.

Dr Carl de Wet: “*Some things just don't have easy answers and that is very unsatisfying and people rely on answers and certainty to live their lives. [We have the] honesty and willingness to address issues that we didn't think through and we'll follow up on this.*”

Throughout the conversation, QH staff were open and transparent about not having all the answers: they acknowledged the uncertainty and frustration about the roll-out across GP practices. This is a cohort which can cope with health professionals being uncertain and not having all the answers, as long as there is a signal from the health professional which validates a consumer’s concern, followed by clear and open dialogue and a sense of next steps. Such an approach builds trust and confidence.

For example, a number of consumers asked detailed questions about anaphylaxis. “I am particularly concerned about the phrase we keep hearing – *that the benefits outweigh the risks...* but the people with anaphylaxis deserve concrete answers to their fears.”

These concerns were addressed by QH staff, explaining how the health system was still preparing how people with anaphylaxis could be safely vaccinated. They were clear that they did not have the answers yet but when they did, these would be clearly communicated.

The relief expressed by both consumers was visible despite QH staff's inability to provide concrete answers at this stage but knowledge of what was happening right now: "Thank you. Much appreciated." "Reassuring to know anaphylaxis is on the TO DO list. We'll relax now until we receive advice. Most grateful."

The importance of transparency around decision-making on vaccine group eligibility

One consumer described themselves as being immune-compromised and having an eating disorder. They completed a pre-screening checklist and told they were in group 1B but has since been told they are no longer in group 1B. They have not been provided with any information about how this decision was made. This is challenging for the consumer, their specialist and others in the same circumstances. The consumer commented: "I think transparency around decisions is so important – particularly to our health professionals who are trying to interpret each of our individual eligibility and safety. It feels challenging when your trusted sources [in this case, the consumer's health professional team] are unsure."

How can Queensland Health ensure a systemic approach of fairness, openness and transparency around these important vaccine group eligibility decisions?

Patience? But aren't we in a hurry?

The clear message from the QH representatives was for consumers "to have a little more patience" with the vaccine rollout in relation to vaccine supply, the appointments process and the response planning for particular issues such as adverse reactions. Yet this is not the dominant message that consumers are hearing from Queensland Health's communications.

One consumer asked, "Can the 'patience' component (with reference to state readiness) be communicated, as there is also a feeling of being pushed and 'strongly encouraged' being predominately communicated."

Another consumer added, "The tone of this debate is shifting from trusting [Dr]Jeannette Young and moving more towards, 'hurry up and why aren't I getting what I want... I just think we are almost at the point of having too much comms. There needs to be some way of making it believable but not as much info as it makes people excited and expectant to be no.1."

The media is louder than Queensland Health

Consumers trust Queensland Health's information yet a number of consumers supported a consumer who observed that most people seem to be getting their information through the media in spite of the volume of web-based content produced by Queensland Health. "The media produces a range of different perspectives [which are] confusing and conflicting e.g. blood clots. We don't seem to have anything from Queensland Health to counteract. The media is louder." Yet another consumer pointed out, "...the impact of reporting... appears to be undermining confidence from what I am hearing."

Are consumers really on their own?

In the absence of tailored information, notifications or contact from trusted health professionals, a number of consumers raised concerns about the onus of responsibility sitting firmly with themselves

in relation to navigating their way through the vaccination process. “It’s a personal thing that everyone is having to do this yourself.” “People are just going by the media and putting themselves into these groups.” “As a carer, my experience has been similar i.e. seeking out information myself about priority groups and where/when/how the vaccines will be offered.” Some consumers also reported that their GPs have not been told anything about what is going on.

Other consumers reported that they have been contacted by their GP and others have gathered information by making appointments with their GP or specialist to consult about the vaccine and the process.

In addition to the individual effort needed from consumers to get the answers they need, this need for individual information is putting additional pressure on primary healthcare services when all resources are needed to deliver 6 million COVID vaccines plus the annual flu vaccines as well as diverting specialist attention from getting back to delivering care as unusual.

Making an appointment online is too difficult

One consumer in his 70s warned that making an appointment for a vaccination through the federal health website is “too difficult” and that many consumers of a similar age would be “lost by having to go through this technical process of registering.”

Helping consumers understand information to know what’s important

A lot of valuable information from Queensland Health’s website was circulated during the Conversation e.g. a list of ingredients for each of the vaccines. However, as one consumer noted, “Some people’s health literacy is pretty low and people don’t understand it. They don’t understand what it is that people need to be considering as important to them.” She went on to recommend additional information possibly with pictures in easy-to-read language.

What is the incentive for people with disabilities to have the vaccine?

One consumer who represents people with disabilities shared his views: “There is no incentive to put in the effort required to go and get the vaccine [for people living with a disability]. The common argument is that it will allow everything to go back to normal. However, for someone who has never had that freedom or luxury to begin with, it really provides no motivation. As a grouping, we are identified as ‘high risk’, yet are not sharing in the benefits of everyone having said freedom back.”

Perhaps Queensland Health needs to consider another narrative for some people who live with a disability to incentivise getting the vaccine. And perhaps Queensland Health could share more widely the resources developed by QDN (Queenslanders with a Disability Network).

www.qdn.org.au/our-resources