

## HCQ Consumer Conversation: The COVID-19 vaccine roll out in Queensland: Are you still on board or are you now feeling de-railed?

### Health Consumers Queensland: Online Consumer Conversation

Date: 27 April 2021 (Consumer Conversation). 20 April 2021 (First Nations reference group)  
Attendees: 24 consumers and carers (many in Category 1B); 7 Aboriginal and Torres Strait Islander consumers; consumer NGOs; Greg Howell, who observed on behalf of the Department of Health's Strategic Communications Branch.

Health Consumers Queensland's latest COVID-19 issues paper explores the impact of the slow progress of the vaccine roll-out program across our states and territories and the decision to suspend the distribution of the Astra Zeneca vaccine for under 50s, on health consumers and carers across the State.

### Reflections from consumers and HCQ and suggestions for next steps

- *"It's time for a 'pause', a chance to all catch our breath and attempt a re-set of our collective understanding of where we are, and what the way forward will look like."*
- There is an urgent need for health professionals known to and trusted by their high risk patients to offer a proactive, joined up, team-centred approach so decisions can be made confidently.
- Offer all consumers a 5-10 minute discussion with a health worker or doctor before they decide to get their vaccination.
- Consumers want to be given the vaccine by someone who knows them and in a safe, trusted environment instead of having to go "doctor shopping".
- Health departments have left trust, good will, and the importance of relationships out of the equation whilst they have been making decisions and issuing directives, damaging their reputation and standing amongst consumers and carers.
- Align and coordinate the messaging and the process to prevent the continued erosion of trust and growing sense of confusion and uncertainty.
- Engage meaningfully with our First Nations leaders and champions and those in culturally and linguistically diverse communities to understand their concerns and work together on solutions to build understanding and confidence.
- Put a high functioning, effective booking system in place e.g. like in Israel.

### Key conversation topics and themes raised by health consumers

#### Decision making without support from trusted health professionals

For some consumers in 1B the decision to have the vaccine has been clear cut– either in their own minds or following a private consultation with their key specialists.

Other consumers who access their care through Queensland's public health system highlighted the loneliness and challenges of trying to reach an informed decision especially if it means coordinating with

a number of specialists in order to reach that decision. Consumers also discussed the challenges of making a decision without access to their trusted specialist or health care team:

*"I think the roll out and information has been really quite lacking from all sorts of departments not least of all from the hospital itself. Being a cancer patient and immune-suppressed, I really can't understand the silence I get from the hospital. I've had better conversations with my GP about getting the vaccine than I've had talking to anyone at the hospital let alone my specialist. That does disappoint and worry me a little bit. Because I have no immune system I would have thought they would pay attention to their high risk patients and keep us in the loop but I've had no notification at all. My GP is all for it but he doesn't want to go and play with my cocktail of medications and then the specialist will go 'oh crap'. He wants to make sure there is the communication between the two of them but I rarely see my specialist these days and there has been nothing [no communication]."*

#### **The constant risk-benefit analysis and assessments consumers/carers are doing, often on their own**

Carers also spoke up about the difficulties of balancing the risks and benefits and the sense of being left out of the picture in terms of decision-making around the vaccine. Often families or those who share a home, are trying to make a decision that works for them all; but doctors will only give advice on "their" patient, not for the entire family/household. *There is a constant risk benefit analysis which we, as consumers, are not so practised in - neither specialist could speak authoritatively on the balancing up - benefit to [child] versus the risk to us."*

People in rural and remote locations are also having to make additional risk-benefit assessments, *"With blood clots and living 800 kms from Brisbane there's no one to help me, so all over red rover. You have to weigh up what your chances are if you have the vaccine."*

#### **The lack of communication, reliable advice and proactivity from medical specialists and GPs**

Decision-making is frustrated by conflicting advice from GPs and specialists. One woman from rural Queensland told us, *"I went to the local GP as concerned about blood clots - he said I could have it (AZ) but specialist said have Pfizer but [my HHS] have not got it."* She added that the specialist had asked her to let him know if she found out where she could access the Pfizer vaccine.

Hepatitis QLD noted a *"lack of proactivity from specialists and identifying who are those patients who would benefit from vaccination."*

While some consumers trust their GP to provide information and the vaccine others do not. *"My GP actually said 'my decision' ...not very helpful unfortunately. And it means I have to rely on the media, Facebook etc for opinions as the facts are hard to clarify."*

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#### *Key messages from First Nations consumers*

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- Consumers, especially Aboriginal and Torres Strait Islander consumers, would like a single source of truth.
  - There needs to be an information strategy for 60s, 70s and 80s year old who don't have social media or who can't read.
  - Consumers would like a 5 to 10 minute discussion with an Aboriginal Health Worker or doctor before they decide to get their vaccination.
  - School students are often a useful source of information sharing and yet school students have been left out of any communications campaigns. Teaming up with Education Queensland, and getting info into kindergartens and day care centres, would be an effective way to share good, clear information that can easily be shared with other family members.
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### **The loss of confidence, trust and pride in the health system and governments**

*"My overwhelming sense is of sadness and disappointment that we've done so well in terms of national cooperation, stopping community transmission and trust in Jeannette [Queensland's Chief Health Officer Dr Young] and Commonwealth to find ourselves now in a position of concern, mistrust, reluctance. "*

*"We started out so well and now we're falling to the back of the pack. Trust is so eroded. Are we going to be able to recover to full trust and full compliance?"*

*"I've lost confidence in the Commonwealth Government roll out.*

*"Promises not kept, confusion apparent, 'we don't need help' attitude, very poor focus in my opinion. This leads me to question just what they know and don't know."*

*"No one is talking about it thoroughly. There is still a lot of stuff they are keeping behind closed doors."*

### **The reality of trying to access vaccines is at odds with the government messaging**

The message has been very mixed and is still confusing a lot of people particularly when the tone of the messaging is urgent yet the booking system and information about locations and availability is not keeping pace. *"Fast tracking Pfizer messages is not reflected in when you are trying to book."*

### **Residential aged care facility staff**

Consumers expressed concerns that these workers have been told to get vaccinated through their GPs. *"It's interesting that staff are not getting vaccines at the same time as residents- especially as staff are the ones going back and forth into the community and are most likely to bring it into the facility."*

### **Vaccine hesitancy and fear**

The recent changes and perceived performance of the roll-out combined with reservations about the long-term effects are leading to people hesitating or adopting a 'wait and see' approach to having the vaccine. *"I'm one of those people who are going to get it when I know more about it. In terms of people I meet, I reckon it's 50/50. There's too much of a rush."*

Hepatitis QLD commented: *"The new decisions have validated the decision to wait so [our community] are not having a conversation with their GP or specialist to find out what is best for them."*

And basic information is still not getting through to people from culturally and linguistically diverse communities. *"People are very afraid and they don't understand."*

### **Reporting adverse reactions – is the negative being overstated?**

Amongst the consumers who had had the vaccine, many had had a positive experience and did not know anyone who had had serious side effects – just *"a bit doughy for the day"*. Some felt their positive experiences were not being reflected in the media. But another said, *"While I agree that the press prefers bad news, I think there is a justification for presenting the public with factual risks."*

Meanwhile: *"One of the main facts that caused me to defer my vaccine was the TGA representative on TV not understanding statistics and comparing vaccine clots to winning Lotto."*