

Health consumers Q&As with the CHO and Queensland Health

In the past 4 weeks, Health Consumers Queensland has hosted two Q&A Forums about the COVID-19 vaccine roll out in Queensland: The first enabled consumers from across our network to put their questions to Queensland’s Chief Health Officer (CHO), Dr Jeannette Young. The second specifically targeted Aboriginal and Torres Strait Islander health consumers who put questions to the CHO and the Chief Aboriginal and Torres Strait Islander Health Officer and Deputy Director-General Aboriginal and Torres Strait Islander Health, Ms Haylene Grogan.

This document is in four parts:

Part 1: Shared themes and differences between the Q&A sessions

Part 2 Summary: COVID-19 vaccine Q&As with HCQs consumer network (held 23 February 2021)

Part 3: Summary: COVID-19 vaccine Q&As with Aboriginal and Torres Strait Islander health consumers (held 4 March 2021)

Part 4: to come after a second Q&A session is held with Aboriginal and Torres Strait Islander health consumers (scheduled for 29 March 2021).

Part 1 – Shared themes and differences

Many of the questions across the two forums highlighted similar concerns or themes.

Shared themes	
Basic information	Consumers needed answers to fundamental questions such as how do vaccines work, how will they be told when they’re eligible, is the vaccine safe especially in the context of their own lives e.g. undergoing chemotherapy, living with chronic health conditions, allergic to some products etc.
Roll-out of vaccinations	There were lots of questions about how the roll-out would happen across the state. Who is in what phases, what definitions are being used in those categories – for example ‘disability’ and ‘disability homes’. How will it work in remote communities, and will those general rules of eligibility apply when vaccinating in a remote community?
Trust and hesitancy	There are varying degrees of trust by people in the system; some trust the research, approval process and the health system to implement the vaccines safely; others do not have quite the same level of trust. This often is paired with a sense of hesitancy. For some they need extra information that is relevant for their own lives and this will increase their trust; and for others their levels of distrust go much deeper.
Communication and education	The need for good, clear communication and education for the whole community was shared across participants at both Q&As.

Differences between the two forums	
Trust	Stems from historical differences. Aboriginal and Torres Strait Islander consumers articulated a lack of trust in many government systems, not just health, that have been present since colonization. This history is deep and impacts on relationships, perceptions and care today and needs to be recognised.
Trusted sources	Consumers are keen to hear from trusted sources – but who those trusted sources are varies across consumers and specifically for Aboriginal and Torres Strait Islander consumers.
Role of health staff	The Aboriginal and Torres Strait Islander Q&A session really highlighted the role of health staff in sharing information, being trusted sources, their relationships and accountability to community and people, and that all of this needs to be considered and acknowledged in policy development, roll-out and communication plans.
Consent	The Aboriginal and Torres Strait Islander consumers raised a number of key questions on consent (consent wasn't even raised as a theme in the other Q&A forum). Consent is key; so having good information/education that supports consent before a person arrives for their immunization, having staff aware of discerning when a 'yes' may mean a 'no'; and ensuring the consent forms and process are easy to understand and to follow.

Part 2 – Summary: COVID-19 vaccine Q&As with Health Consumers Queensland's consumer network

COVID-19 VACCINE ROLLOUT IN QUEENSLAND: Addressing the gaps in information for health consumers and carers

Event: 90 minute online Q&A Forum with Queensland Chief Health Officer, Dr Jeannette Young, hosted by Health Consumers Queensland

Date: Tuesday 23 February 2021

Attended by: 171 consumers, carers and consumer NGOs

Details: Dr Young gave a detailed overview of the rollout and responded to key concerns previously raised by consumers before answering questions posed on the night.

This summary paper highlights the issues/ gaps in information which were consistently raised during the Forum by this diverse group of Queenslanders, many of whom have complex health needs or underlying medical conditions, to support Queensland Health in building widespread consumer confidence in the rollout program.

Recommendations/suggestions

- Offer detail and clarity around the process and interfaces e.g. GP surgeries and pharmacies, as well as the vaccine itself to promote trust and confidence.
- Share updates which demonstrate the process in action - how QH is working to ensure communications meet the information needs of all Queenslanders e.g. engaging meaningfully with diverse groups of consumers and acting on their recommendations.
- Trusted leaders, e.g. the CHO can provide reassurance on key concerns, barriers and blocks.

- People are seeking knowledge and information on different levels and in different formats.
- Given that many people are being advised by Queensland Health to seek their GP or specialist's advice, the gap between what consumers are being advised by Queensland Health and what GPs and practice staff are equipped to offer in terms of tailored advice or pathways needs to be urgently addressed.
- Provide detailed information for consumers and their carers and support workers about the strategies in place to manage different vaccine phase allocations.
- Consumers want more transparency from the TGA in terms of releasing detailed data on the approvals process, safety and efficacy of the vaccines.
- Provide detailed information on the strategies in place for people unable to have the vaccine.
- Provide detailed information on the distribution of vaccine records and what this means for people's lives post-vaccination.
- Although the vaccine is not mandated by the Government, consumers are seeking reassurance that their workplaces will not be able to mandate the vaccine and there will be no impact on jobs if someone decides not to have the vaccine.

Issues / gaps in information

Issue/theme	What are consumers asking?
Confusion and concern around the process: Who is responsible?	<i>How will I know which phase of the program I am in and who will inform me? Do you wait for a notification or do you need to do something yourself to initiate? I don't see how QLD Health would have my information to know that I qualify. Many people have limited records. How are at risk people being triaged to qualify in light of patient files and profiling. Many of us do not have a my health record with the Fed Govt site, only my GP and HHS consultant.</i>
How can we trust the information	<i>How can we be assured that COVID 19 vaccination education and promotion is being focused tested to ensure appropriate use of information, language, images etc There have been inconsistencies in information from Commonwealth to State level</i>
Comparable efficacy of Pfizer and Astra Zeneca vaccines	The CHO responded to many verbal questions on this theme.
How does the vaccine work?	<i>Are the vaccine dynamics readily changeable as the virus changes (for future years)?</i>
Lack of confidence in support for GP Community vaccination programmes	<i>How will GP practices run vaccination programmes without additional resources and funding? Does Qld Health intend to send out as a priority guidelines for GPs who are being approached by their patients who have individual concerns about their particular conditions and the COVID vaccine? When will general practices be informed of their status with regard to providers for 1b populations.2. Simple logistic guidelines for general practices, such as - the National booking system, consent guidelines, wastage With General Practices in our regions in Central Queensland already flat out pre-COVID, and with the COVID vaccine estimated to take 30mins to 45mins to administer, are General Practices going to be provided with suitable funding to secure additional resources to support the on-the-ground rollout of COVID vaccinations to patients / clients? It should be noted that a standard flu clinic can provide up to 3-4 vaccinations per 15 minutes. This is not the case with COVID, we understand.</i>

	<p><i>How could we follow up the 2nd dose of the vaccine in patients who have had their 1st covid vaccine elsewhere when they are not registered with AIR eg visitors. We operate a major General Practice and that information has not been provided direct to our GPs</i></p> <p><i>I have no issues with our GPs knowing how to give a vaccine, I am feeling very under-informed about the logistics of the 1B roll out for medical practices though.</i></p>
<p>Is the vaccination safe for me?</p> <p>Adverse reactions</p> <p>Immune compromised</p> <p>Pregnant or breastfeeding</p> <p>Immune compromised child</p>	<p><i>What studies have been done with persons who are immune compromised? I am HIV+, 64 and I have a real concern of possible complications..</i></p> <p><i>What is the safety profile, or "stats to date" on those with serious health conditions who have had the Covid vaccination?</i></p> <p><i>What is your advice to a person who has had multiple documented allergic reactions to flu vax in the past?</i></p> <p><i>Who do consumers ask about their particular health condition in relation to whether it is appropriate/safe to take the vaccine?</i></p> <p><i>What about children who are immune compromised such as those with chronic health conditions or cancer? Will they be able to access the vaccine IF their families choose to do so?</i></p> <p><i>The final phase of vaccine development is usually a long timeframe to identify any long term side effects / unexpected consequences. given the shortening of the timeframe for the COVID vaccines, how can we be sure of the longer term effects? Will an individual's medical history be part of a risk assessment before a person receives the vaccine?</i></p> <p><i>Pregnant or breastfeeding?</i></p> <p><i>What information is available if concerned about cytokine and bradykin storms?</i></p> <p><i>Is there any risk for people with Vernal conjunctivitis and what priority phase would they fall into?</i></p> <p><i>Are autistic sensitivities/diversities being accounted for in any way systematically? What advice do we give this cohort?</i></p> <p><i>Will residential mental health centres fall in the same category as residential disability services? What about in the case of eating disorders, which are classified as mental health conditions but are often associated with significant physical health issues?</i></p>
<p>Why are carers or support workers not being vaccinated at the same time as vulnerable groups?</p>	<p><i>I am eligible for vaccination as part of Tier 2. However my carer/husband is not eligible. He would like to be vaccinated with me to help improve my safety. Where do carers fit into the schedule?</i></p> <p><i>I have disability and chronic health issues. I live at home, not in residential care. When do the people I live with and my support workers get vaccinated?</i></p> <p><i>Drivers who provide community transportation, including transport patients to hospitals, GPs, which Phase are they in?</i></p> <p><i>Health admin staff are not AHPRA registered - how are they accounted for in the phasing?</i></p>
<p>Transparency of approvals process</p>	<p><i>The TGA is not publishing this safety information to the general public enough to alleviate the anxiety in the community.</i></p>
<p>The vaccine rollout and flu season</p>	<p><i>What gap should people have between the COVID vaccine and the flu shot?</i></p>
<p>Vaccination recording and proof</p>	<p><i>Is Qld Health going to print and distribute the information - screening, vaccine record and post vaccination information</i></p> <p><i>these records are used for an immunity travel passport. How are we providing traceability and proof of vaccination?</i></p>
<p>Queensland Health's long term COVID-19 management</p>	<p><i>Immune compromised people who cannot get vaccines are concerned their life will involve further isolation once vaccines are rolled out.</i></p>

strategies for people who are unable to have the vaccine?	<i>What covid-strategies will be in place after roll out for those in high risk health categories that decline the vaccine?</i>
What does the future look like?	<i>Will the vaccination need to become an annual event? How Qld's vaccine program will be responsive and protect against the new and future strains (will we need boosters?) What percentage of people need to get it, over what period of time, to ensure Qld is covered? When (if ever), are we back to life as usual?</i>
Resolving cross-border hub issues	<i>As a Gold Coast border resident just wondering why Qld based health workers working at the Tweed Heads Hospital are excluded from getting vaccination at Gold Coast hub which is much closer than the NSW hub</i>
Is there a risk the vaccine could be made mandatory by certain workplaces?	<i>Will hospital workers and members of other workforces e.g. hotel quarantine or airlines be mandated to have the vaccine and if they refuse could this impact on their jobs. Will people who work in hotel quarantine areas be permitted to refuse the vaccine?</i>
Workplace or community based vaccination programmes	<i>Will kidney dialysis patients be offered their vaccine at their dialysis units? Will large workplaces have the opportunity to run workplace based vaccination programs</i>

Part 3 – Summary: COVID-19 vaccine Q&As with Aboriginal and Torres Strait Islander health consumers

With Queensland’s Chief Health Officer, Dr Jeanette Young and Queensland’s Chief Aboriginal and Torres Strait Islander Health Officer and Deputy Director-General, Aboriginal and Torres Strait Islander Health, Ms Haylene Grogan.

When: Tuesday 4 March from 6pm to 7.30pm

179 people registered and close to 100 attended (some joined in pairs or groups). People registered from across Queensland: Mt Isa, Bamaga, Tambo, Cooktown, Ipswich, Whitsundays. Many of the people who registered were elders, or people living with complex health needs, or staff who work in health services across Queensland. Their questions reflect what matters to them and their community.

Many questions were asked in the chat about the COVID-19 vaccination and we didn’t get a chance to ask all of them. We have grouped the questions into themes.

Summary of themes: What people were asking

Themes	Specific questions asked by consumers in the chat
Fundamental questions about the vaccine	<ul style="list-style-type: none"> • How does the vaccine work? • How far apart should you have the doses? Will you need yearly top ups? • How safe is it for people with chronic health conditions, allergies, asthma, over the age of 65 and living with a chronic health condition, previous poor responses to vaccines? • Elders present in the room here this evening are very concerned that there has not been enough testing of this vaccine with people who have chronic diseases. They want to know that they will not drop dead from having the vaccine and how it may affect the chronic disease medication they are on. • Can our people on dialysis or transplant, chemo, or post chemo, other immunosuppression, complex comorbidities - go ahead with the vaccine or is it safer to wait?
Clarifying questions about the rollout	<ul style="list-style-type: none"> • How will people in 1B will be notified and the plans for roll-out in remote communities? • How is this different to the usual flu vaccination roll-out? • Is QLD looking to use the ACCHO's / nurse only clinics in remote communities for the Astra Zenica rollout?
Information and communication	<ul style="list-style-type: none"> • How will information be provided at a local level in way that consumers may want it (colourful images, not text heavy) • The need for good, clear, messages that meet the needs of a diverse group of Aboriginal and Torres Strait Islander people for example is there an LGBTIQ+ package for more discrete communities? • Concerned Elders want to know who in the community is going out to explain this to them.

	<ul style="list-style-type: none"> A number of First Nations region-based consumers may be a bit jammie about getting the vaccine and are contemplating going bush as they did in the early COVID days. What additional steps are HHS and QH taking in small remote communities and towns to build First Nations consumer confidence? Especially where First Nations health-workers are non-existent on the ground.
Consent	<ul style="list-style-type: none"> What constitutes informed consent information to be provided to every consumer? How do you intend to provide the education/information to every elderly, disabled, Aboriginal and Torres Strait Islander person in Qld. Questions about how will people consent and how will staff discern when a 'yes' may actually be a 'no'. Can this form be simpler? https://www.health.gov.au/resources/publications/covid-19-vaccination-consent-form-for-covid-19-vaccination
Responsibility for adverse consequences	<p>Who is responsible/accountable for any adverse consequences for the mass roll out? Elders are asking questions wanting clarity about if a Community Council is responsible for allowing the program in the community and consequences of this if there are any side effects. The Commonwealth bought the vaccines and made the plan with the priorities 1a 1b. Are they responsible or the individual health professionals giving the vaccines in community (either at a GP practice, hospital or a community controlled clinic) or is it the Community Council who allowed the vaccination program in?</p> <p>What measures are in place for any adverse reactions to the vaccines and how will individuals be fully compensated for injury during this <i>trial experimental phase</i>? Note the words in italics, it seems that some people feel like this is still in the experimental phases and may feel like test subjects.</p>
Mandatory	Can you tell me if the vaccine will be mandatory for aged / disability home care workers in the community or better still, essential service workers?
Remote/discrete communities	<p>In discrete rural and remote communities will everyone be vaccinated at the same time i.e. community members, health staff?</p> <p>How well equipped are we to handle potential adverse reactions of a remote area consumer to the vaccine? Including the coordination of retrieval flights.</p>

What these questions tell us and suggestions for change/improvement

- The fundamental questions asked about the safety and roll-out of the vaccine demonstrates that key messages are not reaching all of the community. People are seeking answers for their own decision-making and the information they have may not be enough (it might be too general and not specific for their own lived experiences and health conditions).

- Trusted community health professionals and leaders need to be able to share key messages about the vaccine and its rollout across communities in Queensland.
- That a range of communication channels is necessary to reach and reflect the needs of diverse groups within the Aboriginal and Torres Strait Islander people of Queensland including those who live with a disability, multiple chronic conditions, in remote communities, are family carers or health workers, or who identify as LGBTIQ+, for example.
- Given the large number of people who joined were health sector staff, consider hosting forums like this specifically for staff. They are key information sharers and need good information to share with health consumers/ community members.
- Careful thought needs to be given when making policy decisions about the roll out of the vaccine for Aboriginal and Torres Strait Islander people including the responsibility of community elders/owners; how the rollout will impact people in remote communities and what strategies are in place to manage adverse reactions (especially in remote communities); the strengths found in communities across Queensland based on ancient pathways and kinship and how this might support roll-out and information about the vaccine.
- Consider ceding/sharing central control of some of the communications to communities and enabling local leaders to develop their own communications which work for their own communities.
- Addressing the fundamental concerns of safety of the vaccine, and the safety of the roll-out program, is critical to the success of the planned vaccination roll-out for all eligible Queenslanders and specifically, Aboriginal and Torres Strait Islander people. Simply stating that they are safe may not be enough for some Aboriginal and Torres Strait Islander people (and other Queenslanders as well).

Part 4

Summary: COVID-19 vaccine Q&As with Aboriginal and Torres Strait Islander health consumers

With Queensland's Chief Aboriginal and Torres Strait Islander Health Officer and Deputy Director-General, Aboriginal and Torres Strait Islander Health, Ms Haylene Grogan and a panel.

When: Monday 29 March 9.30am to 11am

After this event, we will add to this document with the summary of questions.