HCQ
HEALTH CONSUMERS
QUEENSLAND

Wednesday 23 February 2022

COVID in our communities

First Nations health consumers sharing their experiences from the COVID-19 surge in early 2022.

This issues paper presents back some key discussion points collected from two HCQ online sessions held on Thursday 17 February 2022, with eight First Nations health consumers.

Key issues

- **Getting tested should have been easier than it was**
- **Vax side effects were not talked about enough**
- **Tailored communication is not just about language**
- **Investment in community to disseminate information**
- **Assessing and monitoring misinformation**

COVID from first and second-hand experience

One of our consumers was infected with COVID-19 at the time of the online session. This consumer is a young and healthy person who described the virus as ***"far worse and more rapid"*** than they thought it would be. This consumer explained that even though they considered themselves highly health literate, and did a lot of research about COVID, it did not prepare them for how serious the illness was. This is a concern for other people who may not have done any research at all and got sick, as it would have been a shock to the system for a lot of people.

Another consumer who had COVID in early January, reported that it was interesting to experience the virus after being part of the First Nations COVID-19 consumer reference group. Their symptoms included a ***"sore throat which felt like throat was closing over, hot and cold sweats and fever. The symptoms were very up and down. It felt like a rollercoaster".***

This consumer got tested at a local respiratory clinic. When their positive result came back, a representative from QH called and asked some questions. They then said that a doctor or nurse would be in contact, but the consumer did not get a call back. Further, when this consumer identified as Aboriginal over the phone, the staff member gave them a First Nations specific phone number but could not provide any information about what the number was for. This consumer's partner didn't get a call at all after their positive result and no social supports were offered. Their chemist order for cold and flu tablets did not come.

Another consumer shared how their brother who was unvaccinated got COVID and got very bad symptoms, he even lost 7 kgs while he was sick. He isolated at home with his family and was still experiencing symptoms up to 14 days after testing negative. This consumer stated that her brother seems ***"docile and tired all the time"*** and it is ***"very hard to watch as a family member".***

It was then discussed if the consumer's brother may have long COVID, which sparked a discussion about the lack of information about long COVID, especially for people who have tested positive.

One consumer also shared how their son, his partner and their 18-month-old daughter had COVID. The consumer's 18-month-old granddaughter was the first baby to have COVID in their town, so it was a very scary time for their family (and it seemed to the local health facility). They said that it was very hard to find information, and health services were only visiting for a couple hours a day.

Some consumers shared how their communities came together to look after each other during the surge. In rural areas, some local stores and chemists organised delivery options, and community members did the shopping for family and friends who were isolating.

In a Torres Strait community, a consumer reported that in the first month of January there was about 60 cases every day in a region of 3000 people. Like other remote communities, overcrowding is a major issue in the Northern Peninsula Area, and it was near impossible for people to isolate. So, if someone got sick, it was highly likely that the whole household got sick. The consumer said there is always at least 7-8 people in one house, and it is rare to have less than two families in one home. Because of this, it seemed as though overcrowding was not fully grasped by the Government when planning for COVID. However, after the surge, more places for isolation have been provided and the community is now in a much better position to deal with another outbreak. But the consumer questioned why with two years preparation, there was an initial accommodation gap for those needing to isolate.

Action

- **More in-service education with call centre and all health staff about what supports are available for First Nations people and key messaging.**
- **More firsthand accounts from other First Nations people who have had COVID to share with community.**
- **More promotion about the supports available to people who test positive.**
- **More information about long COVID, especially for people who have tested positive.**

Getting tested should have been easier than it was

Consumers discussed that there were not enough testing services in some communities. One consumer said that they had a cough and wanted to get tested, but the testing clinic was not open until the next day and there were no RAT kits available. When they did get a

RAT kit from the QH-provided testing site, the liquid was leaking from it and it was broken. They could not get another one that day as the testing site was closed at the end of the day, so wonders if any others were damaged too.

Consumers discussed that community wanted to do the right thing and get tested and isolate, but when it is just too hard to get tested, or isolate when you need things from the store, you just do what you need to do. Because of this it is likely that people were still in community and spreading the virus without knowing. ***"If people need things and do not have the support or know of where to get the support, they will probably just go out and get it themselves. This can cause outbreaks, especially in small towns" – Consumer.***

One of the consumers shared that the QAIHC family plan was widely utilised within their community to help people prepare for isolation. This was a good resource and could have been better utilised in more households if they knew about it.

Action

- **More easily accessible information about social supports or suggestions for preparing to isolate**
- **More options for testing**

Vaccination side effects are not talked about

Most consumers shared that the vaccination rollout was good in their communities. In a small rural town, 96% were vaccinated and the reason was because the town has a history of the Spanish flu and the roll-out from the health service was good. Some consumers shared that most people in their community got vaccinated so they wouldn't miss out on going to public places, while others shared that vaccination rates increased significantly when Omicron was in their community.

One consumer shared their negative experience with the vaccination. They got the AstraZeneca vaccination first, which caused excessive menstrual bleeding. When they told the doctor, the doctor told them it was not a side effect of the vaccine (because research did not suggest it at the time). This consumer expressed how this experience took a big emotional toll on them, as they felt like they were not being listened to. Eventually, a nurse who they knew personally advocated for them and they were able to get the Pfizer vaccine instead. The Pfizer vaccine had no side effects. Research is now suggesting that bleeding can be a side effect of the AstraZeneca vaccine. (Association Between Menstrual Cycle Length and Coronavirus D... : Obstetrics & Gynecology (lww.com))

Another consumer shared that one doctor told them that they should get the AstraZeneca vaccine, despite having blood clots. The second doctor who knew her clinical history better, said that they absolutely should not get the AstraZeneca vaccine because of this. A lot of the information in the earlier days was inconsistent. This consumer also shared that their sister was temporarily blind after the vaccine and now has a heart condition that they did not have prior to getting vaccinated.

Consumers discussed how they felt that the side effects was not talked about more. And if it were, it could have influenced their decisions to get vaccinated, or choose a different vaccination. When the information is not clear and transparent, it makes people feel like they are being deceived.

Tailored communication is not just about language

Communications was a major theme across both discussions. The issue was that there was too much generic information available. It was hard to find and too complicated, even for people who felt they had high digital and health literacy.

A consumer from the Torres Strait Islands' community created their own resources specific to their community because they could not find any other suitable resources. They were based on QH and TCHHS posts, WHO resources and an ABC article about ways to reduce transmission. Images of the QAIHC resources on one resource (with a link to it in the caption), and included a QH resource for children in another (with a link to it in the caption).

The resources the consumer developed were translated into Creole and included cultural considerations. These resources were shared across the far north and was even requested by local schools, local Centrelink and shared by the local council.

This consumer stated that although they felt upset and disappointed that their community were not thought of when health resources were being developed, it was a push for locals to raise their voice about communications not being tailored for their community.

Other consumers saw this gap as well and expressed the need for communications to not only have specific language, but to also have cultural considerations. It is very important that people from these specific communities have an opportunity to provide input into the resources developed for their communities.

"There needs to be more investment in community to share information" – Consumer.

Several consumers shared their frustration with the lack of information getting down to the grassroots. **Consumers felt like the main mode of communication was to put information on a website and then hope that people find it.** This is problematic for many community members who may not have access to internet or are not digitally literate.

Some consumers discussed how community spokespeople were helping to distribute the information, however it was not formalised, and they were not resourced or supported.

"Mob know how to talk to mob. It is a missed opportunity when they are not utilised" – Consumer

Having community champions or community spokespeople is especially important in communities where there are no identified health staff. Community is far more likely to

listen to their own community members than the non-Indigenous staff who often do not engage with community outside of their jobs.

There is a need within the communications and engagement space to go beyond creating the resources. The next step is having people in community who can talk through the resources, or health services being accessible to answer questions etc.

Further, one of the younger consumers discussed how they are more likely to listen to health messaging from another young person in a way that they would understand. Now they ask their sister for help and advice, whereas this is not always an option for other people.

The need for more community champions comes from a lack of First Nations health staff. Because a lot of them are too busy, they do not have the time to engage with community. Consumers recognise that workforce is not an overnight solution, but it is an issue that is brought up time and time again in consultations. Workforce is an issue across the board, not just relating to COVID.

Assessing and monitoring misinformation

Although consumers agreed that community champions were a great resource for getting information out on the ground, there was also discussion about the need for people to be monitoring the misinformation shared online as well. Social media is accessible 24/7 and the wrong information on there can be very harmful to communities who rely heavily on it for their news content.

"It is no longer an issue about if the right information is there, now it is a choice for people to take on the right information". – Consumer

One consumer shared how they brought a group of young community members together and helped them to assess information they were sharing online. This included asking questions like: What is the source of the information? What could be their agenda? Is that person who is sharing that information invested in you and your community's wellbeing? Are they sharing this information to help you? Are you sharing this because you are fearful?

They shared that even asking, "where did you get this information?" is enough to get people thinking twice about the content they are sharing.

It was then suggested that there could be some investment into training community people to help monitor misinformation being shared on social media. **"It could be as easy as messaging someone who has shared information saying something like "I know it is an anxious time, I noticed you shared this information, have you looked at the facts here", and sharing the Queensland Health fact checker site with them" -Consumer**.

It is easier for people to reshare misinformation than it is to assess the information or create their own content. The shared content needs to be monitored, because if it is reshared enough, it can create a lot of anxiety within a community.

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Action

- **Invest in community to share information the best way they know how. This investment is needed in people and their time, as well as printers/ink/paper, laminators/laminator sheets and other equipment. It supports community-based organisations (often under-funded) to be prepared for future health campaigns/other campaigns.**
- **More tailored communications that is developed in partnership with people from those communities**
- **Digital literacy education in communities which includes how to assess online information**
- **Train and engage a network of community members to monitor and respond to misinformation online**

HCQ's COVID-19 response

For all HCQ's Issues Papers: COVID-19 click HERE.

This First Nations COVID-19 yarn was a follow up from the *Amplifying Aboriginal and Torres Strait islander voices* project which focused on engaging with First Nations consumers about COVID-19 and COVID-19 vaccinations.

Six months after the final report was submitted, these consultations were an opportunity to hear from the same consumers again and ask about their experiences through the December 2021-January 2022 Omicron surge.

These consultations were undertaken by HCQ First Nations consultant, Lynda Maybanks.

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