



Health Issues Centre
Consumer voices for better healthcare

Report: *COVID-19 – What needs to come next?*

Online Community forum – 11 October 2022



Health Issues Centre

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Executive Summary

The tenth of Health Issues Centre's (HIC) COVID-19 community forums was held on 11 October 2022, titled *COVID-19 What needs to come next?* Invitations were sent to specific organisations and individuals representing particular cohorts. These cohorts were chosen because their voices have often been missing from the policy discussion. They were:

- People with disability
- Culturally and linguistically diverse groups
- Education and young people (particularly those in public-facing jobs)
- Aging (including aged care) - residents, workers and carers
- Immuno-compromised people
- People with social disadvantage

Participation was limited to fifty registrants to ensure both depth and breadth of discussion.

HIC convened this online forum as a component of the [Optimise research study](#), which is seeking to better understand how the community is managing and responding to COVID-19 and the measures introduced to stop its spread.

The information gathered in the Optimise project will help guide Victoria's approach to COVID-19, both to prevent new infections and to reduce the health, social and economic impacts of COVID-19 restriction and prevention measures.

The aims of the forum were to explore consumers' expectations of COVID-19 control measures around the following three dimensions of daily life:

- **Work** – what are the community members' expectations of the future in terms of returning to their workplace and what are their expectations of the employer's responsibility in providing a safe workplace to reduce the risk of COVID-19 transmission?
- **Entertainment** – what are the community members' expectations of entertainment and dining venues they are attending in terms of safety, quality and ventilation?
- **Government** – how would community members like to gain their information from the Government and others related to how COVID-19 is currently being managed and what needs to be done moving forwards?

Key concerns raised by participants are summarised below:

- **People are feeling left behind.** This was largely expressed by those representing the cohorts of immuno-compromised, aging and culturally and linguistically diverse groups.
- **More action and responsibility should be displayed by the government** – particularly in relation to encouraging the uptake of mask wearing.
- **People are feeling concerned about returning to work** – employers should have measures in place to protect their employees' health, such as flexible and remote working options.
- **Messaging and communication from the government has been unclear** and at times, lacking in demographic inclusivity.

- **People are still feeling concerned about contracting COVID-19** and feel reluctant to visit entertainment venues due to the no-longer-present restrictions on density limits and poor ventilation.

This report summarises the questions, comments, sentiments and conversations from the forum under the key themes of: **feeling left behind; government to take on more responsibility; concerns returning to work; unclear messaging; and a lack of COVID-19 safety measures within entertainment venues.**

Introduction

On Tuesday 11th October 2022, Health Issues Centre hosted the tenth in a series of COVID-19 forums, titled *COVID-19 - What needs to come next?* HIC convened this online forum as a component of the Optimise Study which is seeking to better understand how the community is managing and responding to COVID-19 and the measures introduced to stop its spread. The findings of the forum will be used to inform Department of Health planning.

The forum explored what people feel they can manage themselves and what they expect from their work / education environments, entertainment venues, healthcare settings and government.

The aims of the forum were to discuss the following dimensions of daily life:

- **Work** – what are the community members’ expectations of the future in terms of returning to their workplace and what are their expectations of the employer's responsibility in providing a safe workplace to reduce the risk of COVID-19 transmission?
- **Entertainment** – what are the community members’ expectations of entertainment and dining venues they are attending in terms of safety, quality and ventilation?
- **Government** – how would community members like to gain their information from the Government and others related to how COVID-19 is currently being managed and what needs to be done moving forwards?

Forum participants engaged with the speaker and facilitator directly in addition to using the chat function in Zoom.

Information was provided by the speaker and facilitator throughout the presentation and discussion.

The following report provides a thematic summary of participants’ questions, discussion, comments and sentiments.

Methodology

HIC adopted a targeted outreach approach to seek representation from the following specific cohorts likely to be highly impacted by COVID-19 public health decisions and yet often marginalised from policy discussion:

- People with disability

- Culturally and linguistically diverse groups
- Education and young people (particularly those in public-facing jobs)
- Aging (including aged care) - residents, workers and carers
- Immuno-compromised people
- People with social disadvantage

Rather than broadly advertising the forum, individuals were identified by Optimise study and HIC personnel and personally invited to attend via email.

The email included details of the forum such as the aims and objectives. It also encouraged potential participants to nominate and invite 2 people from their cohort. To register their attendance, email recipients were required to access the link within the email that directed them to the Eventbrite page.

A total of 36 registrants attended the forum. A significant portion of the total attendees were those who represented people with disabilities (25%) and seniors (25%). Representation for the cohorts of young people and people who are immunocompromised was limited (each comprising 8.3% of total attendee).

Details of the characteristics of the attendees are reported in the tables below.

Demographic breakdown

Groups of representation	Number	%
People with disabilities	9	25
Seniors	9	25
Young people	3	8.3
CALD	6	16.7
Immunocompromised	3	8.3
Poverty/ Inequality	6	16.7
Other		
TOTAL	36	

Age*	Number	%
18-28	3	10.7
25-34	2	7.1
35-44	6	21.4
45-54	1	3.6
55-64	6	21.4
65+	10	35.7
TOTAL	28	

**Where provided*

Country of Birth*	Number	%
Australia	16	59.3
China	1	3.7
El Salvador	1	3.7
France	1	3.7

India	1	3.7
Iran	1	3.7
Mauritius	1	3.7
Scotland	1	3.7
Thailand	1	3.7
UK	1	3.7
Việtnam	2	7.4
TOTAL	27	

**Where provided*

Speaker

Participants at the forum heard from one expert speaker - Professor Margaret Hellard, a researcher, clinician and Deputy Director at the Burnet Institute.

Over the past two decades, Margaret has focused her work on infectious diseases – preventing their transmission and their impact on vulnerable communities. She has also gained considerable experience in undertaking community-based research involving young people, injecting drug users (IDUs) and vulnerable populations, as well as experience in research in tertiary care institutes.

The key discussion areas raised by the speaker included:

- COVID-19 is not over, and it will continually impact our lives – how do we manage it in a setting that has changed? Particularly now when the government is stepping back
- There is no biologically plausible reason that new variants won't arise. Even if we don't get a new variant coming through soon – we are likely to experience waves of infection as vaccine immunity and immunity post infection wanes
- The exact timing of new variants is uncertain – but it is far more likely to happen than not
- The growing issue and uncertainty of the impact of Long COVID on the population
- Long COVID risk increases with multiple COVID-19 infections – "all the more reason to reduce likelihood of contracting COVID-19"
- The critical importance of up-to-date vaccination status (third and fourth doses) to ensure that immunity doesn't wane too far – particularly as future variants are likely to continue occurring
- Just because a measure is not mandated, doesn't mean it is not effective (i.e., clean air, masks indoors – particularly in crowded spaces, stay home if sick, avoid people who are sick and testing yourself prior to visiting people with major health issues)
- Sustained public health promotion campaigns are effective in leading behaviour change among the population i.e., mask wearing and vaccination uptake and maintenance
- Essentially, how do we change our culture to make measures such as mask wearing a reasonably "normal" practice?

Following a brief presentation by Professor Hellard, a facilitated in-depth discussion was held with forum participants.

Major themes

Feeling left behind

A major theme that became evident within the forum discussion and the feedback that was provided via email response was that, in what feels like the wake of the initial COVID-19 response made by the government during 2020–2021, a proportion of the public are now feeling left behind and unprotected. This is particularly present among members of the community who are highly vulnerable to experiencing severe COVID-19, such as the aging population and those who are immuno-compromised.

“What I find extremely frustrating is that I'm in a very high-risk category and have thus far managed to avoid getting covid however as governments remove all of the remaining mandates, they have in essence made a very conscious decision to make life much more dangerous for those of us who are in high-risk categories should we acquire covid” - health consumer who has experienced poverty or inequality

Carers of the highly vulnerable are also feeling a degree of frustration and a sense that they have been left behind within the decision making led by the Government:

“Just because the majority want it all to be over and go away is not good enough and vulnerable people and their carers feel abandoned, and they are expendable” - representative of seniors and people who are immunocompromised

“My concern going forward is with the removal of a lot of these restrictions and mandates to stay at home is it's really relying on others doing the right thing and do people actually do that in the way that it makes people like myself feel comfortable to go out. In some ways, you feel forgotten” - representative of immuno-compromised people and people with disability

This feeling among these vulnerable populations of being left behind takes on extra meaning when considering that nearly 50 per cent of Australians have at least one chronic condition. Further, most people who have chronic health conditions live in lower-income households, are less likely to be able to afford care, and people in the lowest socio-economic group are more likely to skip prescribed medications and specialist appointments due to cost.¹ This suggests there is more work to do with large numbers of potentially vulnerable populations as our COVID-19 management progresses into the future.

Government to take on more responsibility

The balance between personal and government responsibility raised interesting discussion. It became clear that there was a collective sentiment among the forum attendees across cohorts that the

¹ Grattan Institute, ‘Not so Universal: How to reduce out-of-pocket payments,’ March 2022. Available at: <https://grattan.edu.au/wp-content/uploads/2022/03/Not-so-universal-how-to-reduce-out-of-pocket-healthcare-payments-Grattan-Report.pdf>

government should be taking on more responsibility when it comes to both encouraging a cultural shift towards the uptake of certain behaviours such as mask wearing and ensuring the safety of the community. Although personal responsibility was deemed important, it was highlighted that it shouldn't be relied upon as a main safety measure.

"I am all for personal responsibility but if COVID-19 is running rampant in the community, my personal responsibility alone is not enough to keep me safe" - person who has experienced poverty or inequality representative

"Unfortunately trusting people just to "do the right thing" obviously doesn't work. Without a carrot and stick approach there will not be mainstream uptake of ongoing safety measures" - health consumer representative

"The government approach scares me, I believe we still should be wearing masks, using antiseptic handwash and social distancing and I do not believe taking care of myself and the community negatively affects my life. It frightens me" - seniors representative

Ultimately, although the participants acknowledged the role that personal responsibility plays in the prevention and management of COVID-19, they are also desiring that the *"government lead by example and behaviour."*

Concerned about returning to work

The question of who holds the responsibility for employees' health and safety has been raised as an area for discussion when making the decision to return to work. When people were told that they were able to return to work to accommodate for staff shortages despite symptoms present, one participant stated "How do we protect others in the community – who polices this? That is pretty scary."

"The issue of staff without sick leave and financially needing to work in this environment where people are still dying of Covid. Maybe the government needs an education campaign with big businesses for them to take greater corporate responsibility for this issue" - representative of people with disabilities and those who are immunocompromised

Other comments made surrounding the topic of COVID-19 management within the workplace are as follows:

"Who has the duty of care to handle those who are affected by COVID-19 at work? Are my managers going to think about me and my work?" - consumer and CALD community representative

"Employers should take greater responsibility for not letting staff work when they are sick" - consumer and representative of people with disabilities / people that are immunocompromised

"I wish there was some counter messaging, some alternative to this "return to normal, back to normal", because I mean, it's not very helpful in terms of you know, helping everyone to stay safe and a lot of people do want more flexible work and work from home options at the moment" - representative for youth and people who have experienced poverty or inequality

Another point that was highlighted within both email feedback and chat box discussion was the importance of ensuring workplace flexibility. This would enable individuals to comfortably remain home whilst sick and, most importantly, reduce their likelihood of contracting COVID-19 from within their workplaces and their daily commute.

"There must be flexibility in hours and the opportunity for work to be done from home where possible, but employers will have to step up and may need help to adjust to support these workers in whatever way is necessary" - patient and consumer advocate

Unclear messaging

There was an overarching opinion that during the height of the COVID-19 pandemic, messaging and communication related to COVID-19 facts, statistics and safety measures were unclear and at times, did not accommodate all members of the community. In other words, messaging was not inclusive, nor was it readily accessible.

"I want to talk about messaging, which is very important. I think that what you are getting now is as a kind of contradicting messaging, especially for multicultural communities" - CALD community representative

"How many times did we see important information broadcast without consideration of the need for Auslan and other language interpreters - what about the low vision community, those who don't have immediate access to digital tools?" - patient and consumer advocate

"Provide learning resources with symbols and images that simplify the information delivery making it easy for all to understand" - consumer advocate

“Any messaging must include a range of languages, from the very beginning” - representative for youth and people who have experienced poverty or inequality

It was noted within the forum that information released by the Government should be evidence-based, reporting clearly and accurately on the case numbers using tools across all media platforms. This includes the regulation of information on social media to contain the spread of misinformation.

In terms of encouraging the uptake of mask wearing and influencing a cultural shift to continue this practice beyond its mandate, informative, clear and inclusive messaging was deemed essential. When mask wearing was mandated by the government, community members felt it was enforced in a way that was condescending and ultimately removed their freedom of choice.

“The information was presented in a way that became condescending and lacking nuance coupled with becoming heavily politicised really didn’t help and got a lot of people offside” - consumer representative

“People felt they didn’t have freedom of choice” - seniors representative

“People felt as though they were treated like kindergarten children” - seniors representative

Further to this point, although emphasised as important to containing the spread, it became evident that opting to wear a mask without a mandate raised other significant concerns among some of the attendees, particularly in relation to perpetuating racism and discrimination.

“I worry that wearing a mask when so few people are wearing them will make me look more “Asian” and therefore more likely to encounter racism” - representative for youth and people who have experienced poverty or inequality

“People with different cultural backgrounds, it becomes a stigma to wear a mask. They don't want to do it or they wear it and they wear it wrongly. Then I think education is going to become a main point” - seniors and CALD representative

“ I think people need to see people that they look up to wearing mask so people who they regard as you know, normal ” - representative for youth and people who have experienced poverty or inequality

More safety measures within entertainment venues

Forum attendees raised a number of clear points and suggestions regarding the safety measures for entertainment venues. Gaining more access to information regarding density and ventilation was deemed important by the participants, particularly those vulnerable to COVID-19 such as those who are immuno-compromised and the elderly, as this would enable them to make an informed choice about their level of risk and safety.

“Regarding hospitality and entertainment there needs to be a change regarding cramming as many as possible into dining areas or venues - I worry about the staff as well as attendees. Better ventilation and air purifiers need to be encouraged” - patient and consumer advocate

“Without information on the number of cases (except for a weekly average) it is difficult for people to make an informed decision when going out” - seniors representative

“Why can't provision be made for entertainment venues to provide times when fewer people are in the venue and masks made mandatory at those times?” - seniors representative

The lack of density restrictions and appropriate ventilation within entertainment and dining venues has resulted in many individuals deciding to remain at home. For many, particularly individuals who represent the aging population and those who are immunocompromised, this has become an unfortunate reality and has affected their level of social engagement and subsequently, their mental health.

Questions directed to the speaker

How do we encourage the population to wear masks?

Margaret responded with: "We need to address the politicisation of mask use (i.e., are you a mask believer or non-believer). Within science, belief or opinion doesn't come into the discussion – science is based on body of evidence, not a belief. The body of evidence is clearly on the side of masks being effective, but that body of opinion within the community has pushed back - ultimately leading to confusion surrounding mask effectiveness. To encourage mask use, we need to change our culture. We are capable of this with constant, thoughtful, public health promotion campaigns to inform people about benefits, drawbacks and providing the support to do so."

Is it likely that we will have a regime of annual booster shots?

Margaret stated: "short answer is yes. Whether or not it is needed to be more or less than annually is far from clear. We need to have separate regimes for the vaccine management of COVID-19 and the flu."

What do we need to effectively and safely transit from pandemic to endemic?

Margaret stated: “transitioning from a pandemic to an endemic isn’t necessarily the case. The assumption that we will automatically transition is not proven yet. It often takes a long time to reach endemic.” Margaret takes the approach of “have we got control or some level of control in our pandemic – controlling waves of infections such that they don’t peak so high, don’t cause overwhelm in the health system or overwhelming deaths.”

What did we learn from COVID-19 which we are able to use to manage the next pandemic effectively i.e., are there any guideline, process etc in place?

Margaret responds with “We have learnt a lot – our science has advanced in vaccine technology in a way that is extraordinary. Under certain circumstances people will behave really well if we explain things to them. We saved thousands and thousands of lives from the lockdown last year before delta.”

Limitations

We would like to acknowledge that while we endeavoured to capture different perspectives through the targeted outreach invitation process, the Forum was not designed to be representative of all sectors in the community.

Further research into the effects of COVID-19 on the lives of young people who work in the hospitality industry and the economic drivers and conflicts they experience would in particular be advantageous.

Although this forum was an opportunity for the voices of those who have not typically been well-represented throughout the pandemic within Australia to be given some degree of visibility, the arguments can be strengthened further with concurrent reviewing of supporting documentation such as the Victorian Human Rights Charter and other relevant evidence based systematic reviews and guidelines.

Summary

The forum highlights five key themes government, entertainment venues and workplaces should be cognisant of when moving forward with COVID-19 management.

- 1. Feeling left behind**
- 2. Government to take on more responsibility**
- 3. Concerns about returning to work**
- 4. Unclear messaging**
- 5. Lack of COVID-19 safety measures within entertainment venues**

The results and corresponding themes also illustrate key principles that, if adopted, may facilitate the better management of COVID-19.

- Messaging from the government needs to be clear, inclusive, and acknowledge barriers. When information is relayed to the public, it should be based on evidence and include moderation of social media channels to reduce the spread of misinformation.

- Government figures and people in authority need to model positive behaviours such as mask wearing to encourage a cultural shift. The government should also take on more responsibility to ensure public safety as those who are immuno-compromised and vulnerable to the effects of severe COVID-19 infection are feeling left behind and forgotten.
- Workplaces should remain flexible and understanding of people’s health needs and concerns of COVID-19. Remote working needs to remain an option and if individuals are forced to return to work, appropriate safety measures should be in place.
- There should be a means of knowing what entertainment venues are classified as ‘safe’ regarding the transmission of COVID-19 (i.e., density levels and ventilation) so that individuals can make informed decisions regarding their health and safety.

Appendix: Forum slides



COVID 19 – what comes next

Margaret Hellard

11 October 2022



Optimising isolation, quarantine
and distancing for COVID-19

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COVID LIVE (last updated at 11am 11 October, 2022)

	Total Cases	New Cases Last 24 hs	Active Cases	Current Cases Admitted to Hospital		Total Confirmed Deaths	Lives lost on average each day over the past week
				Hospital	ICU		
Victoria	2,625,569	1,292	7,597	156	7	5,731	6
Australia	10,278,831		42,221	1,484	42	15,383	

Source: <https://covidlive.com.au/Victorian-COVID-19-data-Coronavirus-Victoria>



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Long COVID

- Growing issue – but there is much we don't understand yet
- State Government estimated, based on Omicron infections in Victoria, that 3.3 per cent of the Victorian population are currently experiencing or have experienced long COVID at some point during 2022
- 0.6 per cent have experienced severe long COVID (Victorian Department of Health)
- Global data – some estimates are higher than 3.3% – some lower
- Definition of what constitutes long COVID – not 100% clear.
 - Symptoms for more than four weeks following infection
 - Chronic fatigue like symptoms
 - Post COVID conditions – cardiac disease, respiratory disease, other



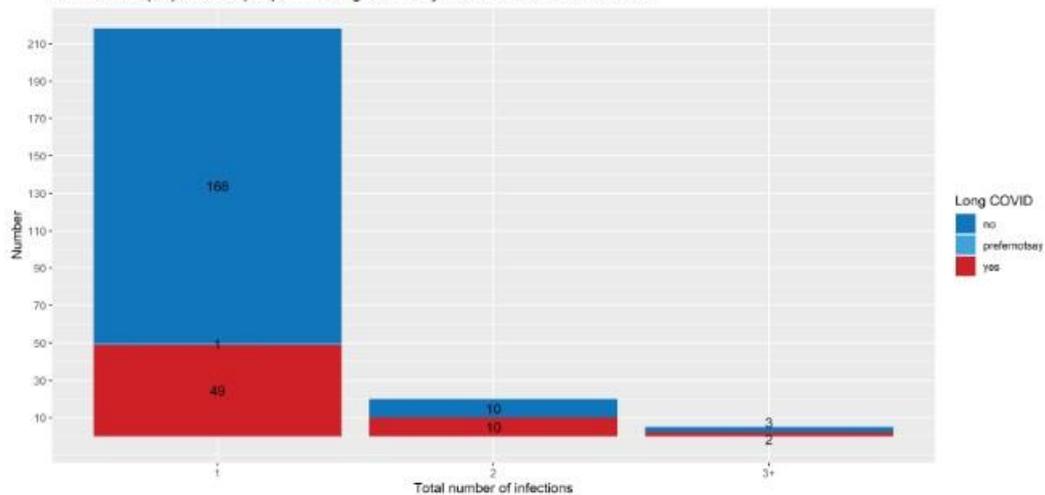
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Long COVID – Optimise study- summary of key results

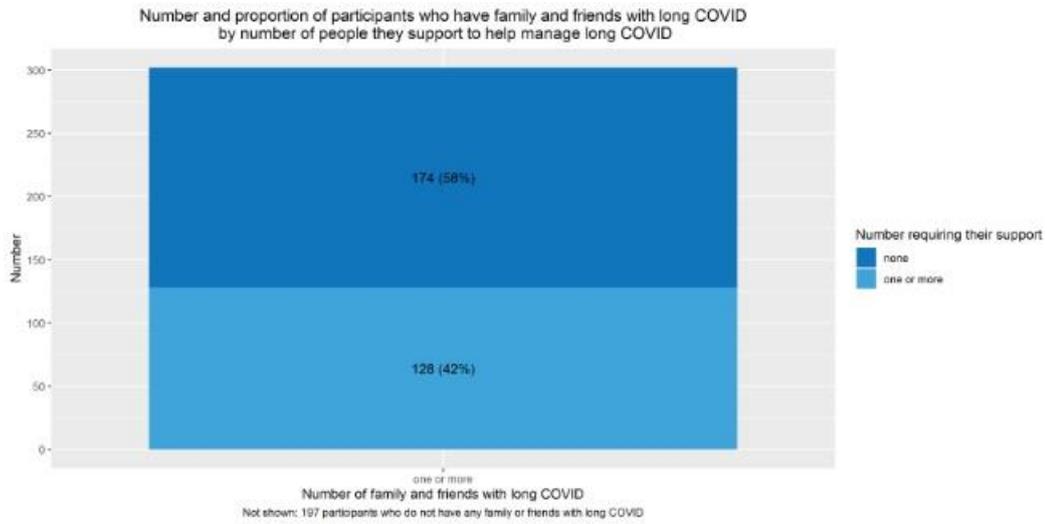
- Two hundred and forty-three (49%) of the 499 participants had been infected with COVID-19 at least once since the beginning of the pandemic
- Three hundred and two (61%) participants had friends or family who had experienced long COVID
- A total of 61 (12%) respondents reported that they had long COVID and 52 completed the extended survey. Of these 52, 43 (83%) said they had long COVID but had not been diagnosed
- Among those who had long COVID, 42 (81%) developed long COVID at their first infection. Since developing long COVID, 6 (12%) had been reinfecte d once and 2 (4%) had been reinfecte d twice
- Among those who had long COVID, 29 (56%) had received three vaccines before the infection that gave them long COVID. Four participants (8%) had not received a vaccine before developing long COVID.
- Since developing long COVID, 28 (54%) people with long COVID had not received any more vaccines
- Of the 302 participants who reported they had friends or family who had experienced long COVID, 128 (42%) reported providing support to this person to help them manage their long COVID.

Infections and long COVID

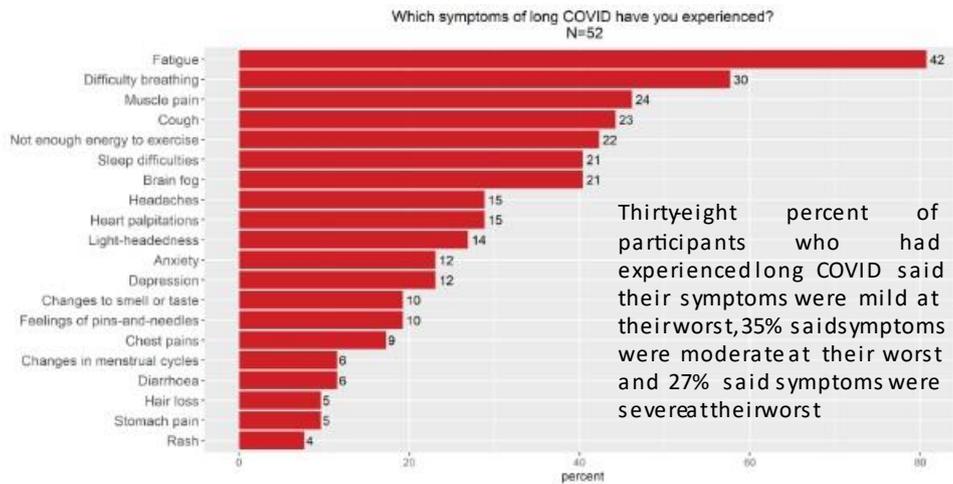
Number and proportion of people with long COVID by number of COVID infections



Number of friends and family with long COVID who require support



Symptoms reported by 52 participants who had experienced long COVID



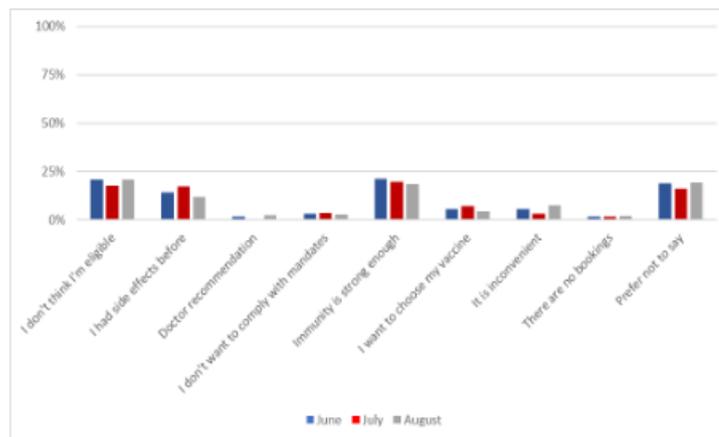
Vaccination

Vaccine Intention

- By August 2022, **10%** (53/536) of participants had received **two** COVID-19 vaccine doses, **47%** (250/536) had received **three** doses, and **42%** (226/536) had received **four** doses.
- In August 2022, the most frequently reported reasons for being **uncertain** about receiving **a subsequent COVID-19 vaccine** dose in the future were: **'I don't think I'm eligible'** (21%, 44/211), **'immunity is strong enough'** (18%, 39/211), and **'I had side effects before'** (12%, 25/211).



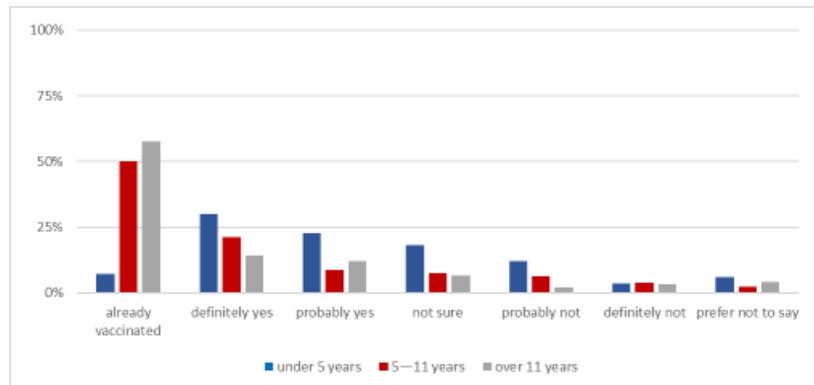
Figure 1: Reasons for uncertainty about further vaccines (N=211)



In August 2022, the **most frequently** reported reasons for being uncertain about receiving a subsequent COVID-19 vaccine dose in the future were: **'don't think I'm eligible'** (21%, 44/211), **'immunity is strong enough'** (18%, 39/211), and **'had side effects before'** (12%, 25/211).



Figure 2: Participants' intention to vaccinate children



- In **August 2022**, **58%** (53/92) children >11ys had '**already been vaccinated**', **14%** (13/92) would '**definitely**', 12% (11/92) would '**probably**' do so.
- **50%** (40/80) of children aged 5 –11ys had '**already been vaccinated**', **21%** (17/80) would '**definitely**' and 9% (7/80) would '**probably**' do so.
- **7%** (6/83) of children <5ys had '**already been vaccinated**', **30%** (25/83) would '**definitely**', and **23%** (19/83) would '**probably**' do so. Although, 4% (3/83) reported they would '**definitely not**' and 12% (10/83) would '**probably not**' get their children <5 years vaccinated.

So what is happening with COVID -19 over the next 12 months

- It is not yet over – unfortunately
- There is no biologically plausible reason that new variants wont arise – this is happening right now
- Even if we don't get a new variant coming through soon – we are likely to have waves of infection as vaccine immunity and immunity post infection wanes.
- The exact timing is uncertain – but it is far more likely to happen than not to happen

So what can we do?

- Vaccination – ensuring immunity doesn't wane too far
- Despite the removal of mandated public health measures – these measures that reduce your risk of catching COVID-19 and/or passing it on to others haven't stopped working
 - Clean air
 - Masks indoors – particularly if very crowded space
 - Stay at home if sick
 - Avoid people who are sick
 - Test yourself prior to visiting people with major health issues



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Thank you

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