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Submission to the Department of Prime Minister and Cabinet Commonwealth Government COVID-19 Response Inquiry

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Summary

This submission addresses the following Inquiry Terms of Reference: **governance; key health response measures; broader health supports; community supports; and mechanisms to better target future responses to the needs of particular populations**. It outlines the key relevant findings from the ‘Diverse Experiences and Understandings of Immunity in the Pandemic Age’ project conducted in 2022-23 and makes recommendations based on this research.

Overview of project

The aim of the ‘Diverse Experiences and Understandings of Immunity in the Pandemic Age’ project was to identify how Australians from specific at-risk social and community groups experience and understand the relationship between immunity and good health in an era in which the risks posed by existing viral infections and diseases are now joined by those from novel diseases such as COVID-19 and mpox. It is a targeted qualitative study that captured insights from 30 participants from four key sub-groups of the Australian population: people identifying as LGBTIQ+, people living with HIV, people living with hepatitis B (HBV), and/or people with lived experience of hepatitis C (HCV)¹. Identifying the different experiences, impacts, causes and effects among these more marginalised, targeted and ‘hidden’ or ‘hard to reach’ populations is vital for a more comprehensive account of how public health and community responses to emerging infectious diseases are currently operating in Australia, and for identifying what improvements could be made in the future.

Participants were eligible to participate if they self-identified as belonging to one or more of the target groups and were aged 18+ years of age and living in Australia. Purposive sampling and screening ensured participant diversity in age, gender, ethnicity/race and geographical location.

The project’s research questions are as follows:

- What does the concept of ‘immunity’ mean for the participants?
- Has this changed for them over their life course, and what experiences have contributed to this change?
- How does the concept of ‘immunity’ fit into their broader understandings of health or ill-health?
- What practices do they engage in to strengthen or protect their immune systems? (e.g. vaccination, medication, infection prevention practices, general good health practices)

¹ People living with HIV, hepatitis B, and/or hepatitis C have unique experiences owing to the biomedical and social natures of these blood-borne viruses, and therefore should not be collapsed or conflated into one group. However, they may share intersecting characteristics, and have crossovers with broader LGBTIQ+ communities.

- How have health communication, public health and community support initiatives helped or hindered participants' efforts to keep well?

The participants took part in a semi-structured interview, which was recorded and transcribed for analysis. Analysis is currently in progress, with an open access research briefing paper already published (available to download at https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4660103). The relevant key findings from this briefing paper are outlined below, followed by recommendations.

Key findings relevant to the Inquiry

Overall, participants responded favourably to government initiatives and responses to the COVID pandemic, particularly those that were offered in the early stages to prevent the spread of the virus. There was broad support of mask wearing mandates, temporary lock downs, and vaccination rollouts. Free access to COVID-related supports were also considered beneficial to maintaining good health. These included ready access to respiratory clinics and vaccinations as well as the temporary expansion of allied health services, such as increased sessions under Medicare-subsidised mental health plans, as well as improved avenues for accessing healthcare, including services that did not require Medicare cards.

For some participants, however, public health orders did not go far enough, especially for those who perceived themselves as immunocompromised or vulnerable to respiratory infection. For instance, some participants believed that the mask mandates were lifted too soon or were not uniformly enforced, and so Australia missed the opportunity to develop a strong mask-wearing culture such as that evident in some East Asian countries. Other participants felt that government may have capitulated too early, or have been too reactive, to negative press around mask mandates. While lockdowns were, on the whole, viewed favourably as necessary to prevent the spread of infection, criticism of made of the lack of wrap around supports, such as housing provision and financial support, that were perceived to be absent during periods of lockdowns. Two participants were also highly critical of state government decisions to reopen schools, highlighting the risk of infection faced by teachers and students.

The relative visibility and use of the Australian Immunisation Register during the COVID vaccination rollout was viewed as ensuring easy access to vaccination information. However, several participants wished that all information on individuals' vaccinations from birth should be as easily accessible. The difficulty of recollection was also exacerbated by different 'service app' requirements and availability in different state jurisdictions (with different access to immunisation registers). Acknowledging the importance of strong personal data privacy and security protections, participants called for better tools to track/record and access health history, as well as automated reminder systems for upcoming vaccinations. The government's electronic health record My Health Record rarely came up in interviews as a way of keeping health records that people could refer to throughout their lives, suggesting either that this initiative has not been well advertised to the community or is being actively shunned.

Participants noted that the improved accessibility of COVID-related supports was also accompanied by greater acceptability on the part of community members. This was especially the case where such supports were community-oriented and promoted a sense of collective responsibility for self and others' health. Respiratory clinics, for instance, were seen as helpful beyond the healthcare that they offered; they were also seen as a version of community support, and there was a demand for more of them. Participants were somewhat critical of the public health reliance on cultivating 'personal responsibility' for pandemic control measures, as this was seen as inadequate as a protection for more vulnerable Australians. This approach was perceived to create divisions between those who care about the health of others and so do the 'right thing' compared to those who wanted a swift return to 'normal'. Participants noted that this division exacerbated existing health inequities. They spoke of new divides between most Australians in good health versus those living with disabilities or chronic health conditions; between various states with differing public health orders, such as between Victoria and New South Wales; and between those who resided in 'fortressed' states, such as Western Australia, compared with the rest of the nation.

Several participants spoke of continuing discrimination and marginalisation and called for more anti-stigma campaigns. Particularly for people living with HIV and those living with HBV, stigma about their conditions had continued during the COVID pandemic. It was common for people to emphasise that there

was an integral role for community organisations to play in relation to providing support and connection as well as providing services such as information and vaccinations. In particular, participants highlighted how community organisations promote and maintain a caring ‘ethos’ towards their community, evident by the numbers of people volunteering in these organisations. This extended to the support provided by community organisations, some of which kept open ‘drop in spaces’ which were perceived to be a great source of support and connection during COVID lockdowns. The perception of community support was amplified through the consistent social media presence (for example, their Instagram and Facebook accounts) that some community organisations maintained during the early phases of the pandemic.

While COVID-related public health orders and initiatives were generally perceived favourably, there was some criticism of public health communication from government and mainstream health services. For example, participants noted the need for better accessibility for health-related information to ensure that ‘information gets out’. This lack of accessibility is also complicated by what was perceived to be a lack of consistent messaging regarding COVID risk and precautions that could be taken. This was especially the case for participants from culturally and linguistically diverse backgrounds, who commented on the ‘muddled’ messaging around COVID vaccination types and eligibility. While the provision of COVID information was initially detailed and frequent, participants noted that there was an increasingly lack of availability of details such as case numbers over time, leading to the perception of declining public interest in COVID safe precautions. Some participants felt that this was due to a lack of visible respect in public forums for ‘scientists’.

In response, some participants felt that government and public health should ‘hand over’ complex health information and messaging to community organisations, as they are able to ‘properly tailor’ such messages. Targeted, non-stigmatising advice that builds on LGBTIQ+ strengths was seen to be a role for community organisations. Such advice extends beyond the provision of COVID-related information to sharing details about good experiences with allied healthcare, such as the circulation of information on LGBTIQ+ friendly services. The idea was that health information should be ‘marketed by community’ but ‘funded by government’. Participants noted that using community or social events to distribute health information was a key strength of community organisations’ communication strategies. Community-led campaigns resonate because ACON, especially, uses ‘real people’ in their campaigns and depend on the role of peers to disseminate information effectively.

Recommendations

The members of the LGBTIQ+ community and people with lived experience of blood-borne viruses who participated in our study offered strong and helpful suggestions for how public health authorities and community organisations can work together to improve public health communication and services related to COVID-19, mpox, hepatitis, HIV, AIDS and other infections and communicable diseases. Our participants’ responses highlight how successful interactions between health communication strategies, inclusive health service delivery, social supports and public health protections, together with community organisations’ services, education campaigns and other supports, can alleviate the impacts of these inequalities.

Health communication and healthcare services that recognise cultural and health diversity and offer clear, regular and updated advice that is non-judgemental and inclusive are highly important. Community organisations that recognise the diversity within their organisation membership and can focus on education and prevention related to the continuing COVID risks as well as the infectious diseases and other health risks with which they were more familiar offer the most helpful support. Finding ways for public health agencies and health communication campaign managers to work more closely and productively with trusted community organisations would strengthen prevention and education initiatives for COVID and other infectious disease prevention and treatment. Expanding free or low-cost healthcare for marginalised groups, including better information about and access to vaccines, would improve health promotion in these communities.