



Commonwealth Government COVID-19 Response Inquiry

Thank you for the opportunity to contribute to the independent inquiry into the COVID-19 response. The Health Care Consumers' Association (HCCA) is pleased to present this submission, sharing the perspective of HCCA's consumer members.

Our submission focusses on three priorities for consumers:

- prioritising clear, consistent and coordinated communication of key health messages both at media events and across the health sector;
- tailoring those messages with specific cultural and communities, including written communication at the recommended reading level; and
- providing clear reasons for the key health messages and any subsequent changes in the light of new evidence.

We also seek to highlight consumer concerns about:

- COVID-19 complacency;
- the effects of and response to long-COVID-19;
- the need for high-quality, evidence based clinical advice that is written in a way that consumers understand;
- a perceived lack of concern for medically vulnerable groups within the community; and
- the need to maintain compassion in health care response settings.

There is much to be learned from the response to COVID-19 that can inform future preparedness and policy settings around emergency responses more generally. This learning must involve listening to the voices of consumers. HCCA would have appreciated more opportunity to comment in order to communicate the complexity and breadth of consumer responses.

We also caution that the COVID-19 response is, in fact, ongoing and must continue to evolve with emerging evidence around the risks, drivers and potential long term effects of COVID-19 infection.

A handwritten signature in black ink, appearing to read 'Darlene Cox'.

Yours sincerely
Darlene Cox
Executive Director

15 December 2023

Health Care Consumers' Association

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About HCCA

The **Health Care Consumers' Association (HCCA)** is the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-Profits Commission.

Terms of Reference

Our response addresses the following Terms of Reference of the Inquiry:

- Key health response measures
- Broader health supports
- Mechanisms to better target future responses

Issues of concern to consumers

Communication

Clarity of communication and transparency around decision making, evolving science and policy settings has been an issue for consumers from the beginning of the COVID-19 response and we suggest that the biggest priority for future public health emergencies must be getting communication right. Effectively communicating complex and evolving science and policy decision making to the public is not an easy task and a tendency to secrecy hampered efforts over the course of COVID-19. This work needs to be done with consumers and communities to ensure our information needs are understood and met.

Politicisation

There is a sense among HCCA's consumer members that the COVID-19 response was highly politicised and that this may prevent the use of effective public health measures in future situations where public good-will is necessary to implement appropriate precautions. An evidence-based response to a significant public health threat should be bipartisan to build public trust and improve outcomes. We believe that the politicisation of the COVID-19 response is likely to impact negatively on the response to any future pandemic and continues to impact decision making around emerging issues related to COVID-19.

PPE

The lack of adequate preparation for a pandemic left the Australian public shouldering the financial or exposure risk burden of Personal Protective Equipment (or the lack thereof) and meant that there was no consistent communication about what was necessary or optimal.

Vaccines

There is a public perception of mismanagement of procurement of vaccines and a vaccine

strategy designed on the run. Communications around vaccines have been, and remain, unclear. The ambiguity of messages needs to be removed. Poor official communication enhances the perception of legitimacy of antivaccine movements, increasing vaccine hesitancy and hampered uptake¹.

This issue continues today with public confusion over who is eligible for and the potential benefits of the XBB 1.5 vaccines and questions about why they have arrived here so long after other countries received them.

Complacency

There is a sense of COVID-19 policy apathy, which may result in increased and avoidable infections with long term consequences we are only now learning about. Consumers have a sense that this complacency is a natural result of prioritising economic factors over health and short-term thinking around infection rates and the potential impacts of COVID-19 triggered disability and chronic ill health.

Publicly available data

The continued reduction in publishing of COVID-19 infection and severity data by all states and territories has negatively impacted the ability of consumers to make informed decisions about their own level of risk. This is particularly relevant in the context of removal of all other public health guidance and protective measures around COVID-19.

The collection, analysis and publication of data should be standardised and prioritised to guide individual as well as policy decision making. The ACT Government stopped publishing monthly COVID-19 data reports on 28 February 2023. In response to consumer requests HCCA now publishes the weekly COVID-19 data on social media.

Clinical advice

Consumers feel there is a need for clear and consistent clinical treatment advice on antiviral medications, including information on and consistency of eligibility criteria and avenues to access treatment if you fall outside those criteria. This could take the form of a Clinical Care Standard developed by the Australian Commission for Safety and Quality in Health Care².

The public needs clear and evidence-based information about infectious periods and infection prevention. This should include clear public messaging around the need for ventilation and triggers and settings for mask use for public health protection.

Long-COVID-19

Consumers remain concerned that the response to long-COVID-19 is inadequate. Dedicated long-CVOID-19 clinics are oversubscribed and do not have the necessary breadth of expertise to assist with the wide variety of health problems triggered by COVID-19. For example, the Canberra Health Service Long-COVID-19 Clinic provides primarily physical and occupational therapy, dietetics, and counselling. Despite what we know about the potential cardio-vascular impacts of COVID-19, relevant specialities are not affiliated with or available to access through the clinic.

Impacts on health services

Consumers continue to be concerned about the impacts of COVID-19 and the response to it on health service staff. It is clear there are ongoing impacts on the health workforce,

including withdrawal from the workforce due to burnout, concerns about health and safety and chronic ill health. Current policy settings have not proven adequate to address the exodus of staff and impediments to recruitment.

Suggested mechanisms to better target future responses

Prioritise health communication (key health messages)

There is a wealth of literature on health and risk communication that addresses both speaking to whole populations as well as groups within the population³.

Communication of key health messages needs to take priority over public affairs/relations, issues management or political positioning.

The health information needs of the public during the initial phase of the COVID pandemic were to understand:

- how COVID-19 was spreading and how to protect oneself from it (on the basis of best available information); and
- any changes in the above as new evidence/data was obtained.

The key health messages needed to be relevant, clear, concise and actionable.

This personal health communication can then be positioned within the groups within which individuals live their lives (friends, families, neighbourhoods, work etc). These key health messages need to include and prioritise the needs of medically vulnerable members of the community.

Health communication (key health messages) needed to be consistent and coordinated across all areas of the health sector

Health communication messages needed to be consistent and coordinated throughout the health sector and at the appropriate reading level for written material. There needed to be a single point of reliable and continually updated communication for consumers and clinicians.⁴

Tailoring and targeting of key health messages to specific cultural and community groups

These consistent and coordinated key health messages tailored to specific cultural and community groups at the local level. Consumers have raised their concerns about the lack of quality, consumer friendly clinical advice⁵ and the lack of tailored communication to particular cultural and community groups.⁶ Written material on COVID was found to be “at or above the recommended grade level, and as such inaccessible to substantial portions of the general public.”⁷

Communicating changes to key health messages

Any changes to key health messages need to be framed in terms of new evidence. All key health messages need to be driven by evidence and communication framed in terms of the evidence.

¹ Rosenthal S, Cummings CL. Influence of rapid COVID-19 vaccine development on vaccine hesitancy. *Vaccine*. 2021 Dec 20;39(52):7625-7632. doi: 10.1016/j.vaccine.2021.11.014. Epub 2021 Nov 13. PMID: 34802786; PMCID: PMC8590511.

² <https://www.safetyandquality.gov.au/standards/clinical-care-standards>

³ For example see Baal, S. T., Walasek, L., Karanfilovska, D., Cheng, A. C., & Hohwy, J. (2022). Risk perception, illusory superiority and personal responsibility during COVID-19: An experimental study of attitudes to staying home. *The British Journal of Psychology*, 113(3), 608–629. <https://doi.org/10.1111/bjop.12554>

⁴ Desborough, J., Hall Dykgraaf, S., Toca, L., Davis, S., Roberts, L., Kelaher, C., & Kidd, M. (2020). Australia's national COVID-19 primary care response. *Medical Journal of Australia*, 213(3), 104-106.e1. <https://doi.org/10.5694/mja2.50693>

⁵ <https://www.hconc.org.au/wp-content/uploads/2022/07/July-2022-health-consumer-living-with-COVID-summary.pdf>

⁶ Smith, J. A., & Judd, J. (2020). COVID-19: Vulnerability and the power of privilege in a pandemic. *Health Promotion Journal of Australia*, 31(2), 158–160. <https://doi.org/10.1002/hpja.333>

⁷ Serry, T., Stebbins, T., Martchenko, A., Araujo, N., & McCarthy, B. (2023). Improving access to covid-19 information by ensuring the readability of government websites. *Health Promotion Journal of Australia*, 34(2), 595–602. <https://doi.org/10.1002/hpja.610>