



# COVID-19 Royal Commission Terms of Reference

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## Introduction

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Consumers Health Forum (CHF) is the national peak body representing the interests of Australian healthcare consumers and those interested in healthcare consumer affairs. CHF works to achieve safe, quality, and timely healthcare for all Australians, supported by accessible health information and systems. At the heart of CHF's policy agenda is consumer-centred care, including government response to pandemics such as COVID-19.

CHF appreciates the opportunity to provide a submission informing the design of the Terms of Reference (TOR) of the Senate COVID-19 Royal Commission (RC). Consumer co-design and engagement reached an all-time low with the COVID-19 pandemic response. Now, however, we are presented with the opportunity to learn from the successes and challenges experienced in the past three years.

## Recommendations

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1. Terms of Reference language must be accessible and understandable.
2. Terms of Reference must actively seek and highlight consumer perspectives.
3. Terms of Reference must investigate and provide recommendations on current issues created by acute COVID-19 infection, and long COVID.
4. Terms of Reference must investigate causes and effects of delayed medical care.
5. Terms of Reference must investigate barriers to mental health support services during and after the acute pandemic stage.
6. The Royal Commission needs to deliver value to consumers by avoiding overlaps with the COVID-19 Response Inquiry

## TOR language and consumer involvement

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CHF calls for TOR language that is **accessible and not obfuscating**. Consumers are eager to contribute with their experiences and require terms of reference written in language that is direct and clear. Only by having TOR that clearly delineate the scope and objectives, will the Royal Commission be able to obtain clear and focussed input by consumers.

**The Royal Commission must also actively seek consumer input and present consumer feedback** as one of the main sources of evidence, rather than simply relying on consumers to provide submissions. CHF advocates for consumer participation that is meaningful, and that avoids tokenistic mention. Additionally, CHF calls for sustainable submission timelines that will allow CHF to cooperate with State-based consumer peak bodies to prepare a joint response to the Royal Commission, and that will provide a coordinated view of consumer views at both federal and state level.

## Current impacts of COVID-19 and Long COVID

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The Royal Commission must strive to be a constructive learning process that investigates the past, present and future of COVID-19 and Long COVID. SARS-CoV-2 is still a novel virus that has been circulating in human populations for a limited amount of time. As such, it must not be thought of as a thing of the past. As of 2022, COVID-19 is Australia's third leading cause of death<sup>1</sup>. **CHF calls for TOR that allow the Royal Commission to analyse and provide meaningful suggestions on present and future challenges related to COVID-19 acute infection.** CHF argues that a good pandemic response is an enduring one.

With 5 to 10% of all COVID-19 cases reporting long COVID symptoms<sup>2</sup>, the **TOR must also focus its investigations into long COVID.** Despite being needed by millions of Australians, specialistic care for long COVID is currently underfunded. This has huge repercussions on individual and population health as well as complex ramifications within the health system. As an important example, consumers living with heart conditions previously considered rare have alerted CHF about being impacted by the rise in prevalence of long COVID. Their specialist clinics are now facing skyrocketing demand due to long COVID increasing the prevalence of rare heart conditions, causing them strain and dangerous delays in care.

## Deferred primary, specialist, and allied health care

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Consumers were severely affected by delays in obtaining the care they needed in 2020. In November 2023, CHF asked consumers to complete a COVID-19-related questionnaire through Australia's Health Panel (AHP) – the CHF interactive platform dedicated to collecting the views of Australians about the state of the Nation's healthcare system<sup>3</sup>. 16% of survey respondents reported delays in obtaining care not related to COVID-19.

Earlier research data from the Australian Longitudinal Study on Women's Health has shown that in 2020, of the women who needed a health service, 25% delayed seeing their GP, 23.6% delayed seeing a specialist, and 45% delayed use of an allied health service<sup>4</sup>.

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<sup>1</sup> Australian Bureau of Statistics (2022), Causes of Death, Australia, last consulted on 21/12/2023 <https://www.abs.gov.au/statistics/health/causes-death/causes-death-australia/latest-release>

<sup>2</sup> Australian Institute of Health and Welfare. (2022). Long COVID in Australia—a review of the literature. Last consulted 18/12/2023 <https://www.aihw.gov.au/reports/covid-19/long-covid-in-australia-a-review-of-the-literature/summary>

<sup>3</sup> "Australia's Health Panel." Consumers Health Forum of Australia, October 12, 2023. <https://chf.org.au/australias-health-panel-0>.

<sup>4</sup> White, Jennifer, Dominic Cavenagh, Julie Byles, Gita Mishra, Leigh Tooth, and Deborah Loxton. "The experience of delayed health care access during the COVID 19 pandemic in Australian women: A mixed methods exploration." *Health & Social Care in the Community* 30, no. 4 (2022): e1384-e1395. <https://doi.org/10.1111/hsc.13546>

As Cancer Australia reports, in 2020 cancer diagnostic and screening services were down by 8% compared to expected numbers, leading to increases in late cancer diagnoses, and poorer health outcomes for consumers<sup>5</sup>.

Considering all of this, **the TOR must investigate the causes and effects of deferred primary, specialist, and allied health care during the acute stage of the COVID-19 pandemic.** The RC must do so by actively involving consumers in developing recommendations on how service delays can be avoided or mitigated in future pandemics.

## Delayed or ineffective mental health support

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Survey studies from the Australian National University's Centre for Social Research and Methods has shown a dramatic increase in psychological distress compared to the pre-COVID period<sup>6</sup>. Whilst at its worst in 2020, rates of psychological distress remained well above pre-COVID levels in 2022<sup>7</sup>.

From AHP data from the November 2023 COVID-19 questionnaire, consumers complained the most about the lack of access and inadequacy of mental health support services. When mental health needs surpassed the scope of practice of helplines – for example - consumers were told to seek help through primary care providers, and left unassisted to navigate Emergency Department visits, GP, and therapist shortages, often incurring prohibitive out-of-pocket costs.

**CHF calls for the Royal Commission to make mental health a TOR priority topic, with a special focus on barriers preventing such services to appropriately meet demand.** Only by actively involving consumers in the re-design person-centred, holistic mental health support services (something that is sorely needed in Australia on a wider structural level) will these services be able to be prepared for the rise in demand that future pandemics will command.

## Value to consumers

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Given the COVID-19 Royal Commission is being carried out concomitantly with the COVID-19 Response Inquiry, CHF calls for the Royal Commission's TOR to deliver the highest value possible to Australian consumers and avoid overlaps and duplication of work. Only when a deep dive into a particular topic would produce new, constructive insight, some overlap is acceptable.

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<sup>5</sup> Cancer Australia. "The impact of COVID-19 on cancer-related medical services and procedures in Australia in 2020: examination of MBS claims data for 2020, nationally and by jurisdiction." (2021). <https://www.canceraustralia.gov.au/sites/default/files/publications/impact-covid-19-cancer-related-medical-services-and-procedures-australia-2020-examination-mbs-claims/pdf/the-impact-of-covid-19-on-cancer-services-in-australia-in-2020.pdf>

<sup>6</sup> Biddle, Nicholas, Matthew Gray, and Patrick Rehill. "Mental health and wellbeing during the COVID-19 period in Australia." (2022). <https://csrcm.cass.anu.edu.au/sites/default/files/docs/2022>

<sup>7</sup> Ibid.