

NAPWHA Submission to the COVID-19 Response Inquiry.

Thank you for the opportunity to provide comment to the Department of Prime Minister and Cabinet independent inquiry into the Australian government's response to, and management of, the SARS-CoV-2 pandemic within Australia.

The National Association of People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people with HIV. NAPWHA's membership of national networks and state-based organisations reflects the diverse make-up of the HIV-positive community and enables NAPWHA to confidently represent the positive voice in Australia.

NAPWHA is indebted to Dr Kerryn Drysdale and Professor Deborah Lupton from the UNSW Centre for Social Research in Health, for provision of their research briefing paper: *Assessments of public health and community organisation responses to COVID-19 and other infectious diseases by LGBTIQ+ people and those living with blood-borne viruses*¹, which has helped to inform this submission.

- **Governance**

Lack of consistency between states and territories in the local implementation of nationally agreed public health and safety actions was a cause of confusion. The public health reliance on cultivating 'personal responsibility' for pandemic control measures was inadequate as a protection for more vulnerable Australians. The dependence on others' good will and conscientiousness to reduce exposure of vulnerable people to the virus is an unreliable method of protection. This approach was perceived to create divisions between those who cared about the health of others and consequently were prepared to do the 'right thing' compared to those who wanted a swift return to 'normal'. Lupton and Drysdale noted that this division exacerbated existing health inequities. Potential for new divides between most Australians in good health versus those living with disabilities or chronic health conditions was highlighted in survey responses.

Pandemic control measures should be mandatory, universal, enforceable, and enforced while they are in place. Relying on altruistic uptake does not work, creates divides, and encourages interpersonal conflict at precisely the moment when community unity is required. Australians excel when there are clear rules, applicable to all.

- **Key health response measures.**

In general, the response to COVID-19 was good. However, for the future improvement of Australia's pandemic response we suggest:

Social conditions are fundamental causes of disease regardless of the type of pandemic, vulnerable, marginalised, and immunocompromised communities will always be at greater risk.² Therefore, these cohorts should always be prioritised for vaccination and other harm mitigations in the first tranches of

¹ Drysdale, K. and Lupton, D. (2023) Assessments of public health and community organisation responses to COVID-19 and other infectious diseases by LGBTIQ+ people and those living with blood-borne viruses. Sydney: Vitalities Lab, UNSW Centre for Social Research in Health.

² <https://pubmed.ncbi.nlm.nih.gov/7560851/>

availability when a pandemic emerges, thus preventing much unnecessary anxiety and avoiding the need to develop rushed plans in the high-pressure environment of a health emergency.

NAPWHA is critical of the unnecessary confusion faced by HIV positive people relating to which vaccination tranche their HIV positive status qualified them for. Initially it was not clear if HIV positive people would be prioritised for vaccination in the first tranches of vaccine availability.

A strict adherence to the science to the complete exclusion of practical implementation did cause problems. NAPWHA made representations to ATAGI, for example, that people with HIV should be prioritised for vaccine access. The HIV positive cohort should not be divided into complex subclassifications such as those who are 'immunocompromised' and those who are not. ATAGI was unable to do this and in the end people with HIV were divided into one group prioritised for the vaccine (people with fewer than 200 CD4 cells/mm³ of blood) and those who were not. As a result, people with HIV had to obtain proof of their CD4 cell level and then disclose that proof to non-HIV specialist clinicians. This meant people with HIV had to navigate the unnecessary risk of unintended disclosure of their positive status leading to stigma and discrimination from healthcare providers administering the vaccinations in the vaccination hubs and centres. The fear possibly acted as a disincentive from seeking vaccination and other protective healthcare. In future pandemics the goal must be to minimise the potential for unnecessary disclosure by prioritising all people with HIV for the vaccine and requiring minimal disclosures of unnecessary health information. NAPWHA notes that despite guidance being given to vaccine centres about a low barriers approach to vaccine administration, part of NAPWHA and our members' work during the pandemic involved responding to services at the local level seeking to collect unnecessary information about HIV status and viral load.

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 in the study by Lupton and Drysdale noted the need for better accessibility for health-related information to ensure that 'information gets out'. Mixed messaging by 'experts' added to feelings of anxiety experienced by many people. The HIV response in Australia is a recent and powerful example that one, authoritative source of trusted and uncontested information is a crucial element to successful pandemic response.

Despite initial concerns about ARV treatment shortages, these did not eventuate. Nevertheless, the Australian experience did produce some important lessons for future pandemics. The contractual agreements with pharmaceutical companies to import sufficient ARVs do not offer protection against significant disruption to global supply chains of the kind we saw during the COVID-19 emergency. Developing a clear understanding of the amount of ARVs necessary for any given timeframe, and present in the country at any moment, would be a good place to start with a view to considering the maintenance and rotation of ARV reserve supplies in Australia. Further, when a pandemic commences panic-buying is a predictable outcome. The rapid implementation of universal and enforceable limits on the number of scripts that can be filled at one time as soon as possible after the onset of a pandemic will, in future, help manage the medicine supply and would prevent the stockpiling of ARVs by individuals.

- **Broader health supports for people impacted by COVID-19**

Participants in the survey administered by Drysdale and Lupton agreed that the implementation of telehealth consultations, extension of Medicare funded programs such as increasing the number of appointments available for people with mental health issues and increase in the number of repeat prescriptions that could be dispensed at one time were very positive actions on the part of government and should be continued. NAPWHA notes that telehealth is an exceptionally positive legacy of the COVID-19 response. The rolling out of telehealth not only helped prevent the spread of COVID-19 while safeguarding access to healthcare services but it addressed long-standing issues of healthcare access more generally. NAPWHA's communities reported high levels of use and satisfaction with telehealth. NAPWHA is critical of attempts to limit its potential almost since its introduction, such as making telehealth availability contingent on having been a patient at a particular clinic for twelve months. **NAPWHA is opposed to the slow removal of telehealth services that we have seen since the end of the COVID-19 crisis, and we urge the government to reinstate telehealth services with a minimal barriers approach to access.**

- **Mechanisms to better target future responses to the needs of particular populations.**

Several participants in Drysdale and Lupton's survey spoke of continuing discrimination and marginalisation. HIV related stigma, particularly, continued during the COVID pandemic. Survey participants residing outside the populous capital cities in the eastern seaboard felt that the 'small town' syndrome, where everyone knows each other or are tightly networked, *inhibited their access* to treatment due to lack of anonymity. That is, people feared accessing necessary healthcare because they were concerned that their HIV status would be disclosed to others or, alternatively, would be used to discriminate against them in the provision of healthcare services. This experience was echoed by members of the Aboriginal and Torres Strait Islander community living with HIV.

Better use of community-based organisations for disseminating health messaging and other information to their communities should be considered as part of future communication strategies in health epidemic and emergency situations as these organisations are seen as providing a 'one true source' of information for the communities they serve. Increase in funding to these organisations to provide enhanced peer support to vulnerable communities in these situations would help to relieve the burden on public health services.

Consideration should also be given to emergency provision and repurposing of private hospital beds to supply non-Covid related public health services, including acute medical and surgical services, at no cost to the public. This would further increase capacity to maintain business as usual and assist in managing wait times for surgical procedures during the pandemic emergency.

Should you wish to discuss any of these issues further, please feel free to contact me: Phillippa Venn-Brown via email to [REDACTED]