



Australian Centre for Disease Control

Submission on Australian Centre for Disease Control Bill 2025

26 September 2025

About Health Equity Matters, Hepatitis Australia and this Submission

Thank you for the opportunity to provide feedback on the Australian Centre for Disease Control Bill 2025 and Australian Centre for Disease Control (Consequential Amendments and Transitional Provisions) Bill 2025.

Health Equity Matters is the national federation for Australia's leading HIV and LGBTIQA+ organisations. We are recognised both globally and nationally for the leadership, policy expertise, health promotion, coordination and support we provide.

Hepatitis Australia is the peak community organisation progressing national action on issues of importance to people affected by hepatitis B and hepatitis C (viral hepatitis). Our members are the eight state and territory community hepatitis organisations.

Australia's record of achievement in responding to HIV, viral hepatitis, and sexually transmitted infections (STIs) is built on the strength of enduring partnerships across the public health landscape - spanning community, clinical and research partners, supported for over four decades by successive governments. The HIV Partnership includes federally funded agencies, such as ASHM and the Kirby Institute at UNSW, the Burnet Institute, the Doherty Institute, the Australian Research Centre in Sex, Health and Society and the Centre for Social Research and Health; alongside Health Equity Matters, that deliver critical activities that inform HIV services across the country. These activities include the development of independent clinical guidelines by ASHM and the analysis of surveillance data and social research by the research institutes. This work is shaped by direct engagement with community organisations and by extension community, ensuring that policy advice to governments across Australia and health promotion to our communities reflect lived experience and emerging trends in community behaviour.

Australia stands on the precipice of eliminating hepatitis B and hepatitis C as public health threats by 2030. This commitment is articulated in successive National Strategies and is the central commitment in the forthcoming Fourth National Hepatitis B and Sixth National Hepatitis C Strategies. Australia's world-leading national response has been built around the principle of partnership that brings together community organisations, clinical leadership, government and research expertise to collaboratively drive policy development, health promotion, expanded access to services, clinical guidance, and surveillance, all informed by the lived experience of affected communities. Community organisations play a vital role in promoting health equity, ensuring that even the most marginalised populations have access to the care and resources they require. Together, these partnerships form the foundation of Australia's globally recognised response to blood-borne viruses, including viral hepatitis, and STIs, and are essential to achieving the shared goal of ending these epidemics.

These approaches are well established and built off decades of collaboration.

Our comments relate to:

- the definition of Public Health Matters;
- sustaining the strength and independence of Australia’s surveillance systems for HIV, viral hepatitis, STIs and related diseases;
- membership of the Advisory Council; and
- the Duty to Publish and exemptions displacing the duty.

The comments relate to our concern that the definition of public health matters and the governance structure of the Advisory Council do not reference consumer or community health. This gap means the CDC’s structure does not embed specialist expertise in consumer and community health in the agency’s functioning or on the Advisory Council. As a result, there is a risk that advice to the Director General will not be routinely informed by, or consider, the needs of communities who are disproportionately affected by infectious diseases.

Recommendations

Health Equity Matters and Hepatitis Australia recommend the enabling legislation:

- Include specific reference to consumer and community health in the definition of public health matters and as expertise required of appointees on the Advisory Council.
- Mandate the inclusion of individuals with expertise in community-led public health action, including a representation of Aboriginal and Torres Strait Islander communities, on the Advisory Council.
- Establish a dedicated Community Committee, chaired by a recognised leader in community responses to communicable diseases, with the Chair serving as a member of the Advisory Council.

Background

These comments are informed by our role as Australia’s national peak bodies for the community-controlled HIV and viral hepatitis responses. Our memberships include state and territory service provider organisations and national peak bodies representing priority populations. These populations include people with HIV, sex workers, people who use drugs, Aboriginal and Torres Strait Islander people, LGBTIQ+ communities, people in prisons, and people affected by and living with hepatitis B and hepatitis C. These communities are embedded in our governance structures, and their health and wellbeing are at the core of our missions.

A distinguishing feature of populations affected by HIV and hepatitis C is that they have been or continue to be criminalised. This history of criminalisation has meant that law enforcement agencies have, and continue to, target these communities. The dissemination of data, evidence, and health advice are critical to support informed decision-making around the development of public policy and service provision planning to protect these communities from health threats. However, this information can also be used to frame certain communities as vectors of disease transmission. By extension, these data and advice are always at risk of being deployed to validate the use of the criminal justice system and policing to deter behaviours – such as sexual practices and drug use – and to monitor communities (gay and bisexual men, Aboriginal and Torres Strait Islander people, sex workers and people who use drugs) who are deemed to be responsible for disease transmission.

Hepatitis B predominantly affects people from culturally, ethnically, and linguistically diverse backgrounds. An estimated 70% of people living with hepatitis B in Australia were born overseas, and 56% speak a language

other than English at home. Many of the estimated 30% born in Australia and infected at birth were born to a migrant parent or parents. Fear that a person's hepatitis B status will negatively impact their migration status and misinformation about modes of transmission is a barrier to testing, diagnosis, monitoring, treatment, and engagement in care. As communities disproportionately affected by infectious diseases, the risk of, or ongoing blame and surveillance means these communities are less likely to attend health services for screening, information on prevention, treatment, care, and support. This situation undermines the investment in public health measures seeking to mitigate the harms of infectious diseases and reinforces the poorer health outcomes experienced by communities disproportionately affected by HIV, viral hepatitis and STIs.

Australia's current approach to the collation and reporting of surveillance data related to HIV, viral hepatitis, STIs and related diseases should be considered world class. For HIV and hepatitis C, this is primarily led by the Kirby Institute at UNSW, which has invested over decades in building strong and trusted relationships with communities affected by HIV and hepatitis C, and the organisations that represent the interests of those communities. For hepatitis B, we additionally acknowledge the Doherty and Burnet Institutes' expertise. Their track records of community engagement provide significant benefits to Australia's affected communities by ensuring that individuals and communities are willing to engage in research and data collection with trust that this information will not be misused. The CDC should not disrupt these existing processes but should rather look to these as models that should be replicated for other infections, diseases, or conditions.

Data Transparency exemptions

While we support the transparency of advice provided by the Director-General of the CDC through the *duty to publish*, we remain concerned that this duty will lead to the publication of advice on affected communities that will inflame the well documented and historical targeting they have experienced by law enforcement agencies and political opportunists. We welcome the exemptions available to displace the duty to publish, in particular, the exemption that includes 'Information that, if publicly disclosed, could present an unreasonable risk of harm to an individual, group or cohort'.

The definition of Public Health Matters and membership of the Advisory Council

We are concerned the definition of *public health matters* and the expertise, qualification and experiences the Minister must consider when appointing individuals to the Advisory Council are not explicitly inclusive of expertise in consumer and or community health. Without this expertise being mandated there is a strong risk that advice provided to the Director-General will not be routinely informed by expertise in these specific areas. This is a situation that could diminish public confidence in the CDC and undermine its capability to develop advice on marginalised populations that have historically had poorer health outcomes in relation to infectious diseases.

The power to establish Expert Advisory Groups has the capacity to resolve this concern, however, this power is at the discretion of the Director General. The absence of community and consumer health expertise in the definition of public health matters and in the qualifications required of Advisory Council appointees means this expertise is not embedded in the fabric of the agency. This leaves the CDC exposed to political expediency, wherein a future Minister for Health who is disinterested in, or dismissive of, affected communities is under no obligation to ensure the Advisory Council includes expertise on the health of such communities. By extension, this means the advice provided to the Director General may not sufficiently sensitise the position holder to the immediate need to exercise their right to withhold the publication of specific advice and/or rapidly establish an Expert Advisory Group to provide targeted advice.

Community public health expertise is distinct from clinical or academic knowledge. It includes applied understanding of how people respond to public health issues in real-world contexts, and how to shape community norms and practices through outreach, peer-led education, and culturally responsive care. This expertise is essential to building trust, ensuring equity, and achieving effective public health outcomes.

To embed this capability structurally, we also recommend the establishment of a Community Committee, chaired by a recognised leader in community responses to communicable diseases, with the Chair serving as a member of the Advisory Council. This model—consistent with the NHMRC—would ensure that community perspectives are integrated across the CDC’s advisory structures and that the agency has access to trusted, real-time intelligence from affected communities, especially during public health emergencies.

Contacts

We would welcome the opportunity to further discuss the issues raised in this letter. To discuss this submission, please contact:

- Health Equity Matters CEO, Dash Heath-Paynter,
or
- Hepatitis Australia CEO, Lucy Clynes

Regards

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