

Hepatitis B Voices Australia: a community led approach for hepatitis B elimination

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Background: The voices of people living with hepatitis B is central to the hepatitis B response and elimination. However, participation by the affected community in decision-making, consultation, and advocacy are limited by multiple factors, including: stigma and discrimination, isolation, inexperience with existing systems for policy development, lack of a safe environment, and limited/no remuneration for contributing expertise. The status quo prevents adequate input from the affected community on issues that impact them, hindering the development and implementation of effective hepatitis B response.

Methods: In November 2022, five initial advocates living with hepatitis B formed Hepatitis B Voices Australia: an independent, non-for-profit community led organisation that supports, represents, and advocates for the health and well-being of people affected by hepatitis B in Australia. We have established a culturally safe environment that focuses on the shared experience of living with hepatitis B, facilitating open conversations and trust.

Results: In our first year of operation, we developed and established key foundational plans and governance structure, policies, and procedures, including: strategic and operational plans; codes of conduct; conflicts of interest policies; and recruitment policies. With these in place, we established formal and informal partnerships, including: memoranda of understanding with HepBCommunity.org and Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM); collaborations with ~20 research projects and grant applications; and participated in >10 advisory group committees. A key contribution has been the community-led consultation process for the National Hepatitis B Strategy 2022-2030. Our work has been promoted at >20 national and international conferences and workshops. We are currently developing our expert advisory committee to ensure central expertise and facilitated engagement.

Conclusion: Effective hepatitis B responses must be led by the affected community. We provide a roadmap and valuable lessons for the viral hepatitis sector and development of similar community groups to enact change in their local regions.

Disclosure of Interest Statement: Hepatitis B Voices Australia recognise the considerable contribution that our partners have made to professional and research activities. We also recognise the need for transparency of disclosure of potential conflicts of interest by acknowledging these relationships in publications and presentations.