

# Beyond Diagnosis: Lived Experiences Shaping the Hepatitis B Landscape

## Authors:

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**Background:** In Australia, hepatitis B virus infection (HBV) is a nationally notifiable disease. Although considered a simple routine process and legal requirement for those conducting follow-up, contact from public health authorities for those living with HBV can be negative and anxiety-inducing. The inclusion of lived experience voices to guide development of notification responses could play an important role in addressing this issue.

**Methods:** An individual with lived experience of both HBV and being followed up after notification to public health authorities in Victoria was recruited as a System Navigator. Initial consultations were undertaken with public health officers (PHOs) and clinicians to better understand surveillance processes, knowledge base and resources used. From these discussions, key activities were identified including:

- Producing video resources with lived experience perspectives of notification for PHOs
- Updating resources, training material, protocols, and call scripts for culturally safe and correct content and accuracy
- Developing additional key resources.

**Results:** The project improved the experience of people living with HBV notified to public health authorities. The input from lived experience led to adjustments in language and approach, ensuring that materials and resources were sensitive to diverse cultural backgrounds. This made the notification process more culturally sensitive and less anxiety-inducing for those diagnosed with HBV. The lived experience video served as an educational tool, providing PHOs with a firsthand understanding of the patient experience, promoting empathy and reinforcing the importance of culturally sensitive communication.

**Conclusion:** Ownership and agency of all aspects of the response to HBV should fundamentally rest with people living with HBV, including the design of public health responses. Making roles for lived experience in research, clinical and public health responses is essential to ensure all aspects of the response are culturally safe, eliminate stigma or discrimination, and ultimately are as effective as possible in responding to the needs of people living with HBV.

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