

Community experiences around Hepatitis B Virus laboratory tests: a needs assessment highlighting neglected psychosocial impacts

Authors:

Tu T^{1,2,4,10}, Heriveau M¹, Bondezi K¹, Guo X¹, Wu A¹, Douglas MW^{1,2,3}, George J^{1,2}, Massie N³, Kiri Lay¹, Nguyen Dinh T⁴, Harrold C⁴, Cohen C⁵, Borondy-Jenkins F⁵, Yakubov R^{4, 5}, Cretu D^{4,5}, Kabagambe K^{4,5,6}, Chanta C^{4,7}, Tran L^{4,8,9,10}

¹ *The Storr Liver Centre, The Westmead Institute for Medical Research, The University of Sydney and Westmead Hospital, Westmead, NSW 2145, Australia.,*

² *Sydney Infectious Diseases Institute, The University of Sydney and Westmead Hospital, Westmead, NSW 2145, Australia,*

³ *Centre for Infectious Diseases and Microbiology, Westmead Hospital, Westmead, NSW 2145, Australia.*

⁴ *Hepbcommunity.org*

⁵ *The Hepatitis B Foundation, 3805 Old Easton Rd, Doylestown, PA, 18902, USA.*

⁶ *The National Organisation for People Living with Hepatitis B, Kampala, Uganda*

⁷ *Pediatric Unit, Chiang Rai Regional Hospital, Chiang Rai, Thailand.*

⁸ *Department of Medicine, Melbourne Medical School, The University of Melbourne, Parkville, VIC 3010, Australia*

⁹ *WHO Collaborating Centre for Viral Hepatitis, Peter Doherty Institute for Infection and Immunity, Parkville, VIC 3010, Australia*

¹⁰ *Hepatitis B Voices Australia*

Background: Linkage to care rates for hepatitis B remain low worldwide. We have shown that psychosocial impacts (e.g., anxiety over disease or transmission, financial strain, and stigma / discrimination) experienced by people living with hepatitis B (PLWHB) influence clinical engagement. A key clinical engagement point is receiving test results. Here, we investigated experiences of receiving lab tests at initial diagnosis of HBV (Hepatitis B Virus) and ongoing management of a chronic infection.

Methods: A 37-item online survey was co-designed with the affected community to understand the experiences and needs of PLWHB during diagnosis and routine monitoring. 40 participants were recruited internationally through community partners and completed the survey on Qualtrics. Eligible participants were ≥18 years old, living with HBV, and able to complete it in English. The 15-20 minutes survey explored information needs and sources, practical and emotional challenges, and willingness to use a webtool to interpret lab results.

Results: Survey results reveal information and emotional gaps after diagnosis, during monitoring, and throughout the care pathway. No participant (0/40) reported receiving adequate amounts of information after diagnosis. Participants needed clear next steps, simple explanations of HBV, reassurance about living a healthy life, access to specialists, and emotional support. Most relied on healthcare providers (25/32 respondents), websites (13/32) or peers (12/32) for information, but found content too technical, fragmented, or inaccessible. 15% reported no confidence in interpreting their own lab results. Only 32% use or are aware of existing digital HBV resources – mainly websites, fora, or social media. Meanwhile, 60% said they would likely use a personalised web-tool (with appropriate privacy, personalization, simplicity, and inclusivity) to understand lab results.

Conclusion: We find a pressing community need for accessible and patient-centred information. We are now co-designing a webtool to provide best-practice recommendations, improve understanding of lab results and empower PLWHB in their clinical management.

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