"I GO AS MUCH AND TO AS MANY DOCTORS I CAN TRUST TO NOT BE STIGMATISED": FACTORS IN THE EXPERIENCE OF HEPATITIS B THAT AFFECT LINKAGE TO CARE AND TREATMENT

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Background:

The WHO 2030 elimination targets for hepatitis B include reducing new infections by 90% and hepatitis B-related deaths by 65%. Expanding diagnosis, linkage to care, and treatment is key to meeting these targets. Understanding experiences of those not currently engaged in clinical monitoring and barriers to treatment and care is vital to improving these rates.

Methods:

An online survey was co-designed with members of the affected community to understand engagement in hepatitis B treatment and monitoring. Participants were recruited from a global online community support group HepBCommunity.org. Survey included both structured and open-ended questions. Suspicious responses were screened out with quality assurance measures. Quantitative data were analysed using simple frequency counts while open responses were coded into NVivo and thematically analysed.

Results:

77 responses (32.5% from Australian residents) were received between May and November 2023. About a third of participants (33.8%) reported >1 year interval since last check-up or had not engaged in care at all. Half reported that they have delayed or cancelled monitoring appointments to avoid stigma, and 57% reported experiencing stigma at their health service. Regarding treatment, two thirds (64%) reported a negative medication experience. For those not taking medication, primary reported reasons included fear of side effects (50%) and unsatisfactory health provider services (33%). Thematic analysis of responses found that clinical monitoring and treatment are influenced by access to (i) affordable services; (ii) social networks; (iii) friendly, confidential, and stigma-free services; and (iv) trusted healthcare providers and pharmaceutical companies.

Conclusion:

HepBcommunity.org can be used to assess the needs and experiences of the affected community not currently linked to care. Our results show that stigma, fear of adverse medication experiences or healthcare system interactions act as barriers to care and treatment. Our work highlights specific areas of need to achieve hepatitis B elimination.

Disclosure of Interest Statement:

HepBCommunity.org and The Westmead Institute for Medical Research recognise the considerable contribution that Gilead has 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.