Expanding community engagement and advocacy in chronic viral hepatitis

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Community engagement and advocacy are important to drive development and improvement of service delivery for chronic viral hepatitis. Community engagement is defined as the process of working collaboratively with groups of people affiliated by proximity, interests, or situations to support their wellbeing.[1] Appropriate community engagement can help to reduce stigma, disseminate messages, and inform intervention development.[2,3] Few hepatitis studies or programmes have shown effective and sustainable community engagement, particularly in low-income and middle-income countries (LMICs). To date, contributions from community-based organisations and advocacy efforts have been focused within high-income settings;[4] however, top-down strategies used in such settings are often difficult to implement in LMICs due to structural, socioeconomic, and cultural differences. The voices of people with viral hepatitis, including those of family members and communities with lived experiences of viral hepatitis, support the development of inclusive, effective, and sustainable health service and policy delivery.

Crowdsourcing offers a unique way of eliciting public input to develop more inclusive health solutions, with groups of people contributing to solve all or part of a problem, and then sharing solutions with the public.[5] In partnership with World Hepatitis Alliance, a global crowdsourcing open call to solicit personal and advocacy stories from people affected by chronic viral hepatitis was organised. Considering the burden of hepatitis in LMICs, the open call was particularly focused on submissions from people in these countries.

The open call was implemented using steps recommended by WHO.[6] We organised a multidisciplinary steering committee including people with lived experience of viral hepatitis, advocates, representatives of community-based organisations, and global and regional hepatitis policy makers from countries with high hepatitis burden to oversee the call. The call was hosted on the NOhep website and promoted globally through social media and through collaborative networks, with 19 962 unique page views.

Although the call was open to anyone, we particularly focused on submissions from people living with or affected by viral hepatitis. Content about personal experiences, local actions from advocacy groups or community-based organisations, community impacts, both before and during the COVID-19 pandemic, were encouraged. Submissions were accepted in the form of text, image, audio or video, or infographics and in any of the six UN official languages. All submissions were screened by two independent judges. Eligible submissions were further reviewed by three independent judges and assigned a score of 1–10 with a higher score indicating a better fit for the judging criteria. The judging criteria were developed based on a consensual assessment technique for novelty and capacity for impact, relevance, feasibility, and elaboration.[7] Submissions were assigned to judges who were native speakers of the submission language. We included three Chinese speaking judges, three Arabic speaking judges, three French speaking judges, three Spanish speaking judges, and eight English speaking judges. These judges were invited on the basis of their practical or research experiences related to viral hepatitis, personal lived experiences, and expertise in community engagement and health communication.

The open call received 119 submissions, 85 of which were eligible, from 27 different countries across five continents. Six were from high-income countries, 64 from middle-income, and 15 from low-income countries. Most submissions were in English (n=55), with other submissions in Chinese (n=12), French (n=8), Spanish (n=5), and Arabic (n=5). There were more submissions from male participants (36 [42%] of 85 submissions) than female participants (23 [27%]). About half had a personal lived experience (40 [47%] of 85 submissions) and more had a family member with a lived experience of viral hepatitis (53 [62%]). Among the 85 eligible submissions, 28 (34%) achieved a mean score of 7 or higher. The submissions included compelling stories from people affected by viral hepatitis and numerous examples of local community-led hepatitis service programmes (appendix).

Submissions receiving a mean score of 7 or higher were selected as finalists and those with the ten highest scores were recognised on the NOhep

For more on the **NOhep Call for Stories** see https://www.nohep.org/stories/

See Online for appendix

website (appendix) with written consent. To facilitate conversations between community-based organisations and policy makers and to spur policy makers' interests in enhancing hepatitis services, we organised national dissemination workshops in Bangladesh and a regional workshop held at the 2021 Conference on Liver Diseases in Africa, and a side event held alongside the 2022 World Hepatitis Summit based on the number of submissions and potential of policy changes.

Our thematic analysis of the 85 eligible submissions identified a broad range of individual perspectives and advocacy strategies within LMICs that were organised using the hepatitis care continuum steps (figure). Advocacy strategies aimed to address common barriers people face in accessing hepatitis care, including awareness and attitudes, availability and accessibility issues, structural obstacles and coordinating care, stigma, discrimination, and misinformation.

The open call findings highlighted the power of community-based organisations and their role in advocacy and leadership to implement, improve, and expand hepatitis services across the care continuum in local settings. Specific examples included an activist from Burundi who established a partnership with local governments and engaged these agencies to initiate hepatitis care and helped expand hepatitis services across the country, leading to implementation of their 2018–22 National Viral Hepatitis Strategy. Additionally, in China, the Yiyou Charity Liver Center re-oriented efforts to address misinformation, and to ensure hepatitis services were delivered within an overstretched health-care system during the COVID-19 pandemic. In India, the Delhi Network of Positive People provided counselling, established a campaign to increase awareness and facilitated mental health and support group meetings and referral to care for people with hepatitis C virus. The Community Network for Empowerment in India initiated a prison intervention programme and conducted a hepatitis B and hepatitis C screening programme at Manipur Central Jail (Manipur, India).

Our findings have important implications for future research and practices. The project provided an opportunity for community engagement and amplified the voices of people with viral hepatitis and advocates for viral hepatitis health-care services. Crowdsourcing can encourage people to share compelling stories and resulted in people-centred solutions that were made open access for future hepatitis interventions. Earlier crowdsourcing interventions have had positive outcomes in increasing hepatitis testing[7] and reducing stigma.[2] Community voices are powerful advocates for expanding hepatitis services. Advocates can act as a link between patients, providers, and policy makers to bridge gaps in the goal of achieving hepatitis elimination by 2030. Community-based organisations have an essential role in helping providers reach hidden or neglected subpopulations, provide holistic care, and sustain hepatitis care for improved clinical outcomes.

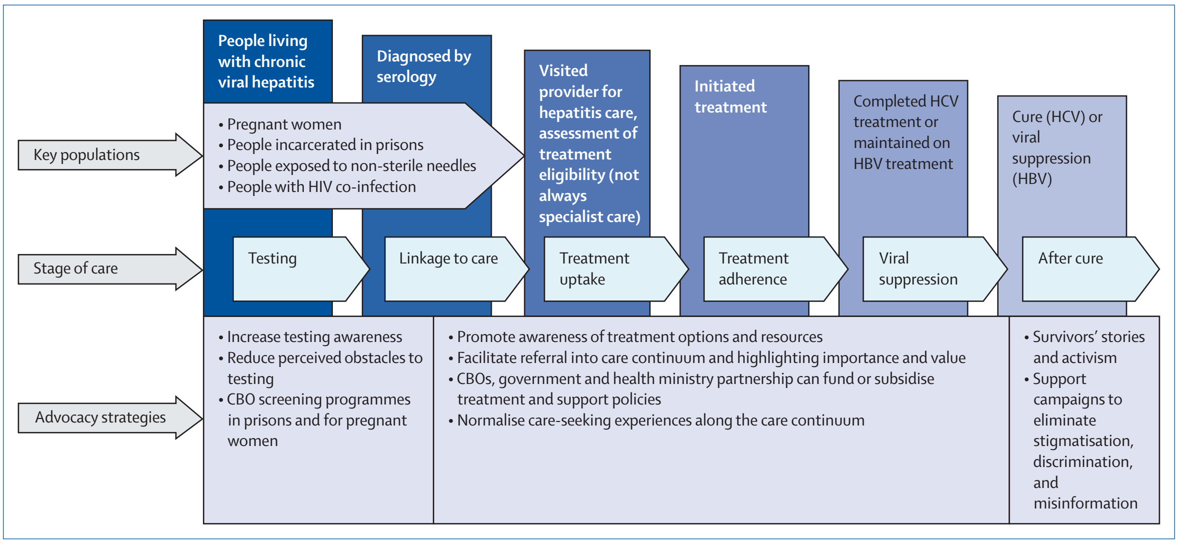

Figure: **Strategies for advocacy in the hepatitis care continuum**
CBOs=Community-based organisations. HBV=hepatitis B virus. HCV=hepatitis C virus.

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