Expanding community engagement and advocacy in chronic viral hepatitis: A global crowdsourcing open call

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Community engagement and advocacy are important to drive development and improvement of service delivery for chronic viral hepatitis. We define community engagement 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 programs show effective and sustainable community engagement, particularly in low and middle-income countries (LMICs). Until now contributions from community-based organisations (CBOs) and advocacy efforts focus within high income settings[4] with these top-down strategies often difficult to implement in LMICs due to structural, socio-economic 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 and where groups of people contribute to solve all or part of a problem, and then share solutions with the public.[5] In partnership with World Hepatitis Alliance (WHA), a global crowdsourcing open call to solicit personal and advocacy stories from people affected by chronic viral hepatitis was organised. Given the burden of hepatitis in LMICs, the open call was particularly interested in submissions from people in these countries.

The open call was implemented using steps recommended by the WHO.[6] We organised a multi-disciplinary steering committee including people with lived experience of viral hepatitis, advocates/CBO representatives, and global and regional hepatitis policymakers from countries with higher hepatitis burden to oversee the call. The call was hosted on the NOhep (a global movement to eliminate viral hepatitis led by the WHA) website and promoted globally through social media and through collaborative networks, with 19,962 unique page views.

While the call was open to anyone, we particularly focussed on submissions from people living with or affected by viral hepatitis. Content about personal experiences, local actions from advocacy groups/CBOs, community impacts, both during normal times and COVID, were encouraged. Submissions were accepted in the form of text, image, audio/video or infographics and in any of the six UN official languages. At the end of the call, 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 native language speaking judges, including non-English ones. Our judges included three Chinese speaking, three Arabic speaking, three French speaking, three Spanish speaking and eight English speaking judges respectively. These judges were invited based on their practical and/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 (55), with other submissions in Chinese (12), French (8), Spanish (5) and Arabic (5). There were more submissions from male (36, 42%) than female (23, 27%) participants. About half had a personal lived experience (47%) and more had a family member with a lived experience of viral hepatitis (62%). Among the 85 eligible submissions, 28 (34.1%) achieved a mean score of 7 or greater. The submissions included compelling stories from people affected by viral hepatitis and numerous examples of local community-led hepatitis service programs (summarized in Appendix table 1).

Submissions receiving a mean score of 7 or greater were selected as finalists and those with the 10 highest scores were recognized on NOhep website (Appendix table 1) with written consent. To facilitate conversations between CBOs and policymakers and spur policymakers' interests in enhancing hepatitis services, we organized national (Bangladesh), regional (Conference on Liver Diseases in Africa) dissemination workshops, and a side event alongside the 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 organized using the hepatitis care continuum steps (Figure 1). 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.

[Insert Figure 1: Strategies for advocacy in the hepatitis care continuum (Adapted from Zhou et al., 2016); CBO: community-based organizations]

Of note, the open call findings highlighted the power of CBOs and their role in advocacy and leadership to implement, improve and expand hepatitis services across the care continuum in local settings. Specific examples included 1) one activist from Burundi who established partnership with local governments and engaged these agencies to initiate hepatitis care and helped expand hepatitis services across the country, leading to their 2018-2022 National Viral Hepatitis Strategy; 2) the Yiyou Charity Liver Center in China who re-oriented their efforts to address misinformation, and to ensure hepatitis services were delivered within an overstretched healthcare system during the COVID-19 pandemic; 3) the Delhi Network of Positive People in India who provided counselling, awareness campaign, mental health and support group meetings, referral to care to people with HCV; and 4) the Community Network for Empowerment (CoNE), from India, who initiated a prison intervention program and conducted a hepatitis B and hepatitis C screening programme at Manipur Central Jail, Sajiwa.

In summary, our study has important implications for future research and practices. The crowdsourcing open call opened an opportunity for community engagement and amplified the voices of people with viral hepatitis and advocates. Crowdsourcing can identify compelling stories and resulted in people-centred solutions which were made open access for future hepatitis interventions. Earlier crowdsourcing interventions have shown positive outcomes in increasing hepatitis testing[7,8] and reduced stigma.[2] Community voices are powerful

advocates for expanding hepatitis services. Advocates can act as a bridge between patients, providers and policymakers to fill gaps in the goal of achieving hepatitis elimination by 2030. Finally, CBOs play an essential role in helping providers reach hidden or neglected sub-populations, provide holistic care, and sustain hepatitis care for improved clinical outcomes, also during emergencies.

Conflicts of interest

DW received funding support from The Hepatitis Fund. JH received funding support from Gilead Science, AbbVie, Janssen, GSK, Roche, and Abbott. PM received funding support from Wellcome Trust and the Francis Crick Institute and UCLH NIHR Biomedical Research Centre, as well as GSK funding to support group members. SW received funding support from Gilead Sciences and honoraria to non-profit organizations. The Hepatitis Fund helped distribute the global open call within the professional networks, disseminate the project findings and coordinate resources for generating impact. Above entities and funding bodies did not play any roles in data analysis, interpretation, study design, or write-up of the manuscript.

Contributor statement

DW and JDT conceived the idea and designed the study. EEK, CLA, TPZ, JH, JW, PE, NW, MHE, SHW implemented the global crowdsourcing open call and collected submissions. EEK, TPZ and DE cleaned and analysed data, generated figures and tables to present findings. EEK, DE, TPZ, DW wrote the first draft of the manuscript. All co-authors provided constructive comments and edited the manuscript. All authors have seen and approved the final version of the article.

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