Best practices for engaging with communities affected by hepatitis B

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Background/Approach:
Developed voices from communities affected by viral hepatitis are crucial for designing and advocating for effective solutions in the health system. However, engagement between affected communities and professional societies, industry, and other stakeholders remains difficult due to variable understanding of the roles, capacities, and expertise of people with lived experience.

Analysis/Argument:
We developed guiding principles governing how these stakeholders should engage with the affected community. We use here as a case study chronic hepatitis B, a condition associated with significant stigma, informed by first-person experiences of people living with hepatitis B.

Outcome/Results:
To address this, people with lived experience of hepatitis B and representatives of 15 patient advocacy groups developed several consensus viewpoints to enable respectful and effective partnership with affected communities. These include:

1. Partner with advisors early and throughout the project design, providing opportunities for actionable input into the process.
2. Budget for advisory time and remunerate advisors appropriately for their expertise.
3. Invite more than one advisor.
4. Recruit lived experience advisors through established community groups.

5. Provide contract agreements that are easy to understand and equitable.
6. Choose the right level of engagement.
7. Ensure accessibility of briefing information ahead of meeting.
8. Recognise the technical support needed to optimally engage.
9. Be mindful of advisors during a meeting, actively seek out their counsel, and engage with them.
10. Ensure safety and respect boundaries regarding confidentiality, privacy, and disclosure.
11. Train staff working with communities in trauma-informed practices and cultural safety.
12. Provide cultural and emotional support to lived experience advisors.
13. Debrief with advisors and include them in follow-up steps.

Conclusions/Applications:
We propose that this list of 13 best practices should be incorporated into any engagements with communities affected by hepatitis B, and that these practices can be generalisable to other conditions.

Disclosure of Interest Statement:
TT, NY, LT, and KN are founders and board members of Hepatitis B Voices Australia. CC is president of the Hepatitis B Foundation; FBJ, YI, and BZ are employees of the Hepatitis B Foundation. TT, LT, SW, JC, WL, BA, KK, SB, CM are members of the Hepatitis B Foundation Community Advisory Board. KK is president of The National Organisation for People Living with Hepatitis B, Uganda. SC is the founder of Hepatitis B Companion. AM and IP are employees of ASHM Health. ID and MK are members of ELPA.