HIV Cure Research Crowdsourcing: An Author Response

Joseph D. Tucker^{1,2} Alice Zhang³ and Yang Zhao¹

EDITOR: WE WOULD LIKE TO THANK Robert Reinhard for the thoughtful letter in response to our research article.¹ We agree that creative responses are necessary to push this field forward and that we ought to have high expectations of the researchers and community members involved. At the same time, we would like to respond to three of the points raised in the letter: more detailed analysis of subgroups who participated (e.g., people living with HIV [PLHIV] vs. local residents); our depiction and definition of HIV cure; and how the crowdsourcing results were disseminated to researchers, policy-makers, and community leaders. We define crowdsourcing as having a group solve a problem and then sharing that solution with the community.²

First, our crowdsourcing contest was intentionally designed to increase participation from subgroups that suffer from stigmatization and marginalization. Individuals who participated in our contest were allowed to choose how much (if any) information about their identity they wanted to share with the contest organizers. This style of having a truly open call is consistent with the preferences of PLHIV and a larger crowdsourcing literature.³ We acknowledge that this limited our ability on the analysis side, but this was an important step in encouraging broad participation.

Second, we agree that the meaning of HIV cure is complex and goes well beyond single examples, such as Timothy Ray Brown. This was precisely our rationale for having extensive in-person events (see Fig. 1 in Zhang *et al.* article in this issue) that provided an opportunity for individuals to not only receive pamphlets but also to ask questions and obtain individualized feedback. We acknowledge that the meaning of HIV cure will, in some ways, be dependent on what information is provided. We chose to include our exact pamphlet content as supplemental material to transparently convey what participants were provided.

Third, we wholeheartedly agree that community input is essential for driving research and policy. Crowdsourcing carries an ethical obligation to share the fruits of the crowd with the wider public responsible for generating these insights. Our crowdsourcing contest was followed by a series of

three local events with local stakeholders (including hospital leadership, community leaders, key populations, and policy-makers) to disseminate these findings. A concise policy brief in Mandarin was also prepared and distributed to local stakeholders. The PowerPoint slides of the in-person presentation were made publicly available on our crowdsourcing contest website.⁴ It is our hope that the crowdsourcing contests created greater dialogue between local community members and researchers, facilitating exchange and paving the way for enhanced collaboration in the future.

Author Disclosure Statement

No competing financial interests exist.

References

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Address correspondence to:
Joseph D. Tucker
UNC Project-China
Guangdong Provincial STD Control Center
2 Lujing Road
Guangzhou 51009
China

E-mail: jdtucker@med.unc.edu

¹Institute of Global Health and Infectious Diseases, UNC Chapel Hill, Chapel Hill, North Carolina.

²Faculty of Infectious and Tropical Diseases, London School of Hygiene and Tropical Medicine, London, United Kingdom.

³School of Medicine, University of Maryland, Baltimore, Maryland.