

TRUST, RESPECT AND RECIPROCITY UNDERLIE THE PREFERRED WAYS OF COMMUNITY ENGAGEMENT IN HIV BIOMEDICAL RESEARCH: FINDINGS FROM A QUALITATIVE INVESTIGATION IN INDIA

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BACKGROUND

Meaningful community engagement (CE) in HIV prevention research is crucial for the study's success and is an ethical obligation. We used data from a qualitative study to identify expressed and implicit reasons behind community representatives' preferred ways of CE in HIV biomedical research/trials.

RESULTS

Participants' narratives unfolded both explicit and implicit reasons for the preferred types of CE. Trust was a central theme: trust on the sponsors based on their reputation/credibility, trust on the study as it was endorsed by trusted NGOs, and trust based on how the communities were engaged (as community advisory board/CAB members, and/or as field research staff). Trust seemed higher with diverse CAB (e.g., diversity in gender, socioeconomic status) as diversity was seen to allow/encourage diverse opinions. Participants' expectations regarding capacity building of CAB members (improving decision-making skills) and field research staff (community members co-producing knowledge) reflect actions that could increase trust. Other preferred CE activities seemed to symbolize respect and dignity: e.g., providing appropriate monetary compensation, constituting formal community review/monitoring mechanisms. Reciprocity was inferred by the importance placed on exploring communities' needs, sharing the findings with communities, and using the findings to inform policies/programs, in collaboration with communities. Transparent communication with communities was explicitly stated as critical for gaining and maintaining trust.

METHODS

This exploratory qualitative study was conducted in partnerships with seven NGOs and community advocates. NGOs helped in recruiting a purposive sample (maximum variation sampling) of diverse participants from key populations such as men who have sex with men, transgender women, people who inject drugs and female sex workers, and general populations (adults, adolescents/youths). We conducted eleven virtual focus groups (FGs) between July and October 2021. Data were explored from a critical realist perspective, using framing analysis (examining how the participants framed the narratives). The analytical focus was on 'why' the participants wanted particular kinds of CE.

CONCLUSIONS

Trust, dignity, respect, and reciprocity underlie community representatives' preferred ways of CE. For researchers and sponsors, this means that CE is not to be seen as a checklist of activities to be done, but whether those activities convey dignity and respect, demonstrate reciprocity, and gain and maintain trust.

Figure 1: Roles of Trust, Respect and Reciprocity in Successful Community Engagement



Table 1. Illustrative Quotations for preferred ways of community engagement

Trust is developed by prolonged engagement and communications
"Before doing the research, some people will keep 3-4 sessions just to talk to you, just a hangout with [research team]. If they do like that then you get familiar and you feel that you know this person to some extent so the consent that I give [is based on trust]." (FG1, MSM)
Lack of reciprocity (e.g., sharing findings) decreases trust
"They do not trust anybody because their trust has been broken so many times so they don't want to trust anyone. They will listen to my story and write a book on it and in return they don't get anything so why should we tell our story to anyone and why should we trust anyone?" (FG5, FSW).
Treating with respect and dignity increases trust
"If you give money [compensation] then it is like [we are] getting respect. I feel that that I have done something good and in acknowledgement I have received cash or in kind". (FG4, PWID - Women)
"I am a drug user and living with HIV for several years. I have participated in a couple of studies and have co-authored articles that were published in [international journals]." (FG3, PWID - Men)

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