

Community Engagement in HIV Vaccine Research: A Multiple Embedded Case Study in Canada, India, South Africa and Thailand

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BACKGROUND

- Recognition of the importance of community engagement in HIV vaccine research
- Few studies have identified and assessed stakeholder roles and challenges for community engagement in diverse country settings

FOCAL QUESTIONS

- What are appropriate roles of community stakeholders in HIV vaccine trials?
- What are the challenges to meaningful community engagement?

METHODOLOGY

Design

- Embedded exploratory case study with a multiple case design

Settings

- Toronto and Ottawa, Canada
- Johannesburg, South Africa
- Chennai, India
- Bangkok and Chiang Mai, Thailand

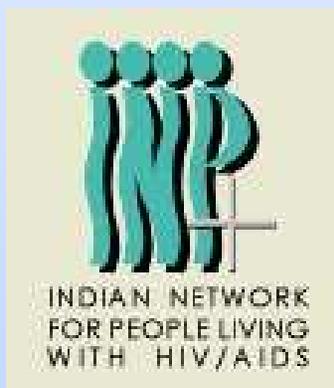
Data collection

- In-depth, semi-structured interviews
 - persons from populations at higher risk of and living with HIV
 - community advocates
 - service providers and HIV experts
- Community focus groups among populations at higher risk of HIV exposure

RESULTS

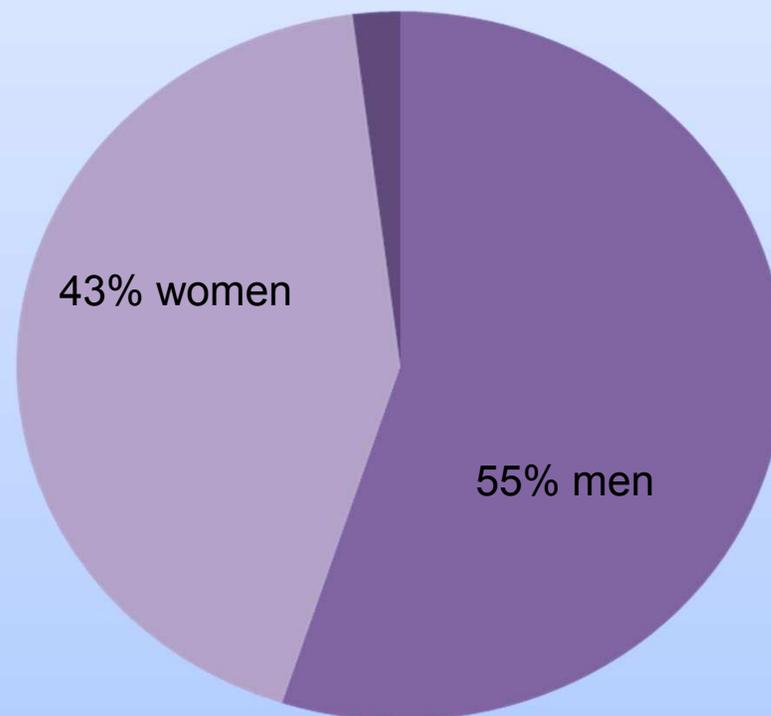
Participants (n=183)

- 92 individual interviews
- 10 focus groups (n=91)



Gender

2% transgender women



Cross-cutting Themes

Identification of genuine community

“There are a lot of difficulties with CABs in and of themselves – are they hand-selected? Are they elected? Are they selected by the research institution? Do they have autonomy from the research endeavour?”

Altruism

“I care about the future, I care about society, and I care about culture. I care especially about Indian folk; I care for my people. I want to help the women. What’s a needle? If it’s gonna save lives, tell me more.”

Trial literacy

“Research literacy is absolutely important and the job is on civil society groups to do it; because when it’s done by the researchers, it looks like social marketing and all you want to do is make sure people accept your research, rather than coming from a neutral perspective.”

Late invitation to engage

“An ideal model of community engagement would involve communities during protocol formulation stages to determine the community’s perceptions of the social value of the research”

Cross-cutting Themes

Mistrust of medical research

Most of these trials are deliberately conducted among people who are economically disadvantaged and who are from developing countries...I even doubt whether Phase I trial among normal human volunteers was actually conducted.

Appropriate roles for community stakeholders

“...to expect somebody after six months on a community advisory board to be equipped to make key decisions about how these things are going to get designed and implemented is naive.”

Dissemination of information

“Often negative perceptions about trials emerge because of how these are reported in the media, and indicate a failure on the part of the researchers to properly engage all relevant stakeholders”

Dealing with negative trial results

“People get ready psyched up and invested in a trial...and for something to end early...people seem to be always caught by surprise, even though that’s something that as a researcher I know is always a possibility. I don’t think we communicate that possibility as well as we need to.”

LMIC-specific Themes

Economic imbalances

“I would rather see CABs where there’s an external independent organisation that builds their respective capacity and so, they can indeed be, independent in their assessments and information and perspective about the trials.”

Sustaining support for CSOs

“....Communities need to be engaged more over the life of a trial. They should not only be engaged during community meetings when trials are recruiting and then again when results are going to be announced: this does not constitute meaningful community involvement.”

Local vaccination cultures

“People take the little snippet of information they’re given and they wrap it into their local belief systems...and from there try to make sense of it. And it’s not surprising that there are just incredible amounts of misunderstanding about how a vaccine works.”

INTERPRETATION

Interpretation

Meaningful community engagement in HIV vaccine research challenges us to:

- Identify appropriate roles for community stakeholders commensurate with their time and expertise
- Engage civil society organizations (CSOs) early in the trial planning process
- Maintain transparency in information shared and bridge siloization of knowledge among CSOs
- Support capacity-building and sustainable community infrastructure despite the episodic nature of clinical trial implementation

ACKNOWLEDGMENTS

