

**Stakeholder-based
Recommendations for
Good Participatory Practices (GPP)
in Biomedical HIV Prevention Trials
in Thailand**

Introduction

Goal

To explore stakeholder-based recommendations for Good Participatory Practices (GPP) in Biomedical HIV Prevention Trials in Thailand

Objective

To collect and analyze interview and focus group data from a variety of Thai stakeholder groups.

Method

Sample

Three types of participants were involved:

- 1) researchers and research site staff,
- 2) non-governmental organization(NGO) and community-based organization (CBO) staff,
- 3) community members, including biomedical HIV prevention trial participants.

Interviews

Interviews explored recommendations for community engagement and participatory practices including

- community advisory mechanisms
- standards of HIV prevention
- informed consent
- communication

Process

Interviews were

- audio recorded
- transcribed
- translated as necessary
- thematically analyzed

Results

- 14 Key informant interviews
- 3 Focus Group Discussions

Based on participant responses, what follows are 12 recommendations for Good Participatory Practices in Biomedical HIV Prevention Trials in Thailand:

1) Engage

Good trial-related community practice engages with potential research participants and their communities.

It encourages communities to learn and share trial-related information and knowledge.

Community has a right to be engaged. They have the right because what we are doing, we are doing in the community. We are doing to the people. They have the right to know what we are doing to them; right to know the result. They have the right to know what's going on.

Researcher

2) Expertise

Representatives of key stakeholder groups such as IDU and sex workers have invaluable knowledge and experience.

Their expertise can help guide recruitment and retention, and development and delivery of a standard of prevention.

3) Prejudice

Genuine engagement will not be possible in the presence of prejudice.

Prejudice can be from research teams towards community members or from community members towards research teams.

I think there can be prejudices between the community and the researchers. In this case, prejudice refers to the mistrust among each other. But if a mutual understanding could be established from the first place regarding the objective of the research, the community and the researchers would be able to share a common goal.

NGO Member

4) Inclusive

Meaningful engagement requires accepting the input from all different types of stakeholders.

This means including input from people who are low in social status or have low levels of education, income or literacy.

5) Sustainable

Community engagement could be most effective when research protocols and the researchers and teams implementing those protocols have clear plans for creating and sustaining that engagement.

Plans and mechanisms for community engagement activities should begin prior to the start of a trial.

Community could be involved at the study design stage or the design operational plans.

6) Supportive

Effective community engagement requires that trial entities support comprehensive means for participants to safeguard their well being across the life of a trial (for example through stable access to clean injecting equipment or condoms).

7) Training

Training for people involved in community advisory mechanisms helps them to be effective advisors to researchers and trial staff.

This training may require both dedicated funding and enough time and a commitment for ongoing training.

Ongoing training is necessary because the knowledge needs of advisory mechanisms can change during the course of a trial.

We need to be trained to understand that we can withdraw at any time. We need training about the principles of human rights and the principle of ethics for the research. We need to understand what the things are that violate the principles of ethics.

Community Member

8) Sensitivity

Sensitivity training is important because many people hold prejudicial attitudes about high-risk groups.

Such sensitivity is necessary for communication and understanding.

Sensitivity training is a way to strengthen the quality of community engagement.

9) Community Advice

Recognize that Community Advisory Boards (CABs) are not the only effective form of community engagement.

There is an important need to explore other forms of soliciting community advice.

Sponsor-mandated community advisory mechanisms can grow beyond only a requirement of funding, to be a successful part of a trial.

10) Beyond Trial-specific Community Advice

Consider the creation of local or national community advisory mechanisms not necessarily trial specific but ongoing beyond the length of an individual trial.

Like a national human rights committee but a national CAB committee, which could operate in the same way as a national human rights committee. In other words a unified CAB network that would help to make the CAB's voice heard privately, publicly or even in the government sector.

Community Member

11) Network Community Advice Mechanisms

Consider mechanisms to support and to enrich researchers and community advisory mechanisms at a network level, and not only at an individual level.

Networks could help researchers to learn about good participatory practices from other researchers. Networks could help community advisory mechanisms learn about research processes from other community advisory mechanisms.

12) Invest in Community Advice Mechanisms

A lot of time and investment is necessary to form and train a community advisory mechanism.

Therefore, donors and sponsors could consider ways to maintain funding between studies.

This funding would enable community advisory mechanisms to continue. This way, it would not be necessary to form and train a new advisory group for every trial.

Conclusion

All respondents strongly expressed that social and power dynamics could prevent genuine community participation. Thus, effective and genuine participation would require recognition of and attention to these dynamics.

Participation is a political process. Let's be honest and frank about this. That's what it is.

Researcher

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