

Conclusions and Recommendations of the HIV Prevention Trial Network on Community Involvement in HIV Prevention Research

As this document illustrates, community involvement is an integral part of successful research. Two primary objectives in collecting and publishing these lessons learned are to achieve a deeper understanding of the role of community involvement and collaboration in research, and to share knowledge and experience for how existing sites can refine and strengthen their community programs.

The conclusions and recommendations provided here are drawn from the combined wisdom of many people. First, we invited research sites to submit articles about their community programs, the challenges they faced in implementing them, and the lessons they learned in the process. Each of the articles identified what they felt were their most important lessons learned on the following topics in HIV prevention trials:

- How to approach the community for involvement
- How to effectively provide training for community members
- How to ensure community involvement with research methodology and design
- How community advisory structures can be developed
- How community representatives can make a difference

In an effort to synthesize the conclusions or recommendations of the lessons learned articles as well as to incorporate experience and knowledge from those sites in the HPTN that did not write an article, the lessons learned from each of the nine sites were consolidated into one document. The HPTN CORE community program staff then presented them to the participants at the 2005 HPTN Combined Regional Working Group Workshop in Rio de Janeiro, October 23-28, 2005. In the workshop's Community Educators session, 30 participants representing community educators, study coordinators, principal investigators and other research staff were asked to create a unified document with recommendations across all of the HPTN. The group was divided into five groups and was asked to:

- Group similar lessons into one and formulate in clear and concise language
- Add lessons that are missing

The following are the consolidated and revised conclusions and recommendations from the nine lessons learned articles with additional input from participants at that workshop.

1. How to approach the community

The research team should:

- Know the community and its needs and develop good relations with them
- Hold open meetings between the research team and the community
- Incorporate suggestions from the community into the community education plan
- Respect cultural diversity and local languages
- Involve a communications professional in developing messages that educate and provides clear information
- Consult with the community about its research needs and assure that proposed research projects are relevant to local communities
- Involve the community at the earliest stage of designing and planning the protocol
- Involve opinion leaders, health professionals, politicians and other direct and indirect stakeholders at the local and national levels
- Involve community workers and leaders; with their familiarity, knowledge and experience, community members have the ability to identify and solve communication problems and distrust by building a transparent and trusting relationship within their communities

2. How to effectively provide training to community members

Community members should be provided training to:

- Understand scientific design, protocol development, and informed consents
- Assess the ethics of proposed science
- Develop successful strategies for delivering information to diverse groups affected by science;
- Identify barriers in reaching communities and develop skills to address and overcome these barriers
- Assess resources to support training (i.e. participatory approaches to community involvement, rapid assessment, male involvement, media communication)

3. How to ensure community involvement with research methodology and design

- Simplify study design and methodology and introduce it gradually so that CAB members feel knowledgeable and are comfortable to discuss and make suggestions to inform protocol development.
- Write protocols as a narrative/summary for dissemination to the CAB for review and discussion. This will enhance the feedback from the CAB to researchers to ensure valuable community involvement in protocol development.
- Ensure that CABs understand that they may not be able to contribute to the development of all protocol related issues.
- Make sure that research reflects the goals of the researcher and interests of the community so that the HIV prevention research agenda is locally and globally relevant.

- Involve CABs in translation of study documentation to ensure that they are culturally sensitive and linguistically correct.
- Involve CABs in dissemination of preliminary findings

4. How community advisory structures can be developed

CAB Subcommittee

- Research teams have learned a great deal from subcommittees specific to a study population, including how they function, their impact on research and community activities, and their limitations.
- Create sub-CABs to advocate for the concerns of diverse sub-groups within the community. This practice has been somewhat successful, but more work needs to be done to address problems of representing highly diverse communities.

CAB Function

- Create a well-balanced CAB structure (direct versus indirect stakeholders, male versus female, representatives from cross-sections of society).
- Identify and retain productive CAB members, which is a challenge
- Ensure the community advisory structure represents the voices of all groups in the community, especially the most vulnerable populations

CAB Principles

Ensure that CABs should remain voluntary and autonomous in their advisory roles and do not become employees of the project. A CAB member who is an employee has a conflict of interest and interferes with their function as advocates for the community.

CAB Meeting Process

Use facilitators in CAB meetings to ensure that the agenda is not dominated by senior and more experienced CAB members.

5. How community representatives can make a difference

Recruitment and Retention

- Community representatives help direct research teams to the proper target population. This facilitates study recruitment and enrollment as well as the validity and reliability of the study.
- Community representatives can provide advice on the best way to approach HIV-positive participants. This helps create a good relationship with the target community and fosters effective community education activities.
- Community representatives can instill trust among participants that helps create a favorable impression of the research process.

Representation

- HIV prevention research would benefit from a larger cohort of role models and leaders, including scientists and principal investigators, who are representative of the communities from which participants are drawn.
- We need to recruit people who reflect the current demographics of the epidemic.

Mobilization

- CAB members can work to lessen the stigma that prevents people from accessing information and effective treatment.
- Confidentiality must be maintained by all project staff members and CAB members to protect the privacy of participants. Failure to do so may lead to a stigmatization of participants and the start of rumors surrounding the research.
- Community representatives can make a difference in the outcome of HIV prevention trials by effectively mobilizing their communities.

Advocacy

- The same CAB can serve multiple, similar projects; however, the creation of a national CAB network offers a greater opportunity for CABs to improve and expand their advocacy efforts.

Community Education

- Planning and development of education activities and information dissemination should be ongoing activities.
- It is possible to work with districts/municipalities to develop low literacy information/education materials on general HIV transmission prevention issues.