

Enhancing Community Participation in HIV Prevention Research

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Introduction

- The HIV Prevention Trials Network (HPTN) is a collaborative of 26 international research sites established to evaluate the safety and efficacy of non-vaccine HIV prevention interventions.
- HPTN has established Community Advisory Boards (CABs) at each site to promote community-centered, relevant and ethical research.
- The Specific Aim of this study was to assess the views of CAB and research team members regarding community consultation in HIV research.

Background

- Community Advisory Boards (CABs) in AIDS research have their roots in AIDS activism
- NIH requires AIDS clinical trials units to establish local CABs
- The role of CABs is to provide advice and communicate community preferences

Questions

- Are CABs an effective way to enhance community participation in HIV research?
- Do CABs work in the absence of organized activists?
- Do CABs work in prevention trials vs. treatment trials?



CAB Chair
Epworth, Zimbabwe

Methods

- We used rapid assessment methods
- Goal is a preliminary, qualitative understanding
- Field teams conduct site visits
- Triangulation of data sources —secondary reports, ethnographic observations, semi-structured interviews
- Key Informant Interviews
 - 36 CAB members
 - 31 research team members
 - 33 potential participants
- Six sites and CAB history are described in this chart:

	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
Philadelphia										
Harare										
Birmingham										
Chiang Mai										
Lima										
Los Angeles										

Data Analysis

- Interviews transcribed
- Data entered into Ethnograph
- Reviewed for broad themes and subthemes
- Codes assigned and verified
- Summaries and cross-site analysis

Results

Role and responsibilities of CAB

- Bridge, link, go-between, liaison
- Provide advice on protocols
- Identify potential research ideas
- Clearinghouse for ethical issues
- Legitimize research in communities by responding to misinformation, providing access, and public relations
- Some tension about roles reported

“To whom is the CAB accountable? Is it to the community? Is it to the local municipal authorities? Or, is it to the research programs? That is a gray area. That is an area we are struggling with.” — CAB Member

Identifying Ethical Issues

- Ethical issues permeated interviews with both CAB members and research team members
- CABs view themselves as protecting vulnerable people
- Participants and CAB members often from poor or stigmatized groups

“Are we being sacrificed in order to develop a better product?”— CAB Member

Why People Serve on CABs

- Concern about impact of HIV on their community or population
- Personal experience. e.g., HIV-infected
- Opportunity to learn about other agencies, research, influence policy
- Reimbursement — lunch, tokens, travel and stipends
- Prestige — self worth; having something to contribute

“Just being part of something that means something. Sometimes when you are a drug user or ex-drug user. You know, being a part of something good and right means something.”— CAB Member

Models of CAB Organization

- Broad Community Model
 - Cross-section of larger community (Chiang Mai, Harare)—government officials, educators, religious leaders, NGO representatives, people living with HIV
 - Long term view of mission
 - Want sustainability
- Population Specific Model
 - Needs of a specific group
 - African Americans, Women, IDUs, MSM
 - Protocol driven (Birmingham, Philadelphia)
 - Preparedness driven (Lima, Los Angeles)

Conclusions

CABs appear to be an effective strategy for enhancing community participation in HIV prevention research. CABs also appear to be effective in the absence of AIDS activists and in prevention trials.

Recommendations

- Develop strategies to make CAB meetings more productive
- Bring debatable issues to the table
- Continuous formal and informal training to respond to disparities in knowledge
- Cross site networking for CAB members
- Train researchers in talking to community
- Community building and leadership training as part of CAB development
- Develop plans for timely feedback of research findings to communities

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