

# Assessing Community Involvement in HIV Prevention Research: Process, Results, and Application of Findings

S. Morfit<sup>1</sup>, J. Stanton<sup>2</sup>, W. Wilson<sup>2</sup>, S. Kirkendale<sup>2</sup>, J. Frohlich<sup>2</sup>, and S. Morin<sup>1</sup>

<sup>1</sup>University of California, San Francisco; <sup>2</sup>Family Health International

## Background and Introduction

- Community involvement in HIV prevention research has become increasingly common; however, evaluation of such partnership approaches has been limited.
- Monitoring and evaluation are essential for strengthening community involvement in research and identifying challenges to collaboration.
- The aim of this project was to design and implement a survey assessing community participation in the HIV Prevention Trials Network (HPTN).
- HPTN is a collaborative of 26 international research sites established to evaluate the safety and efficacy of non-vaccine HIV prevention interventions.
- HPTN has a policy to promote community involvement in HIV prevention research. At the site level, the community is typically represented by Community Advisory Boards (CABs) and other consultative structures.

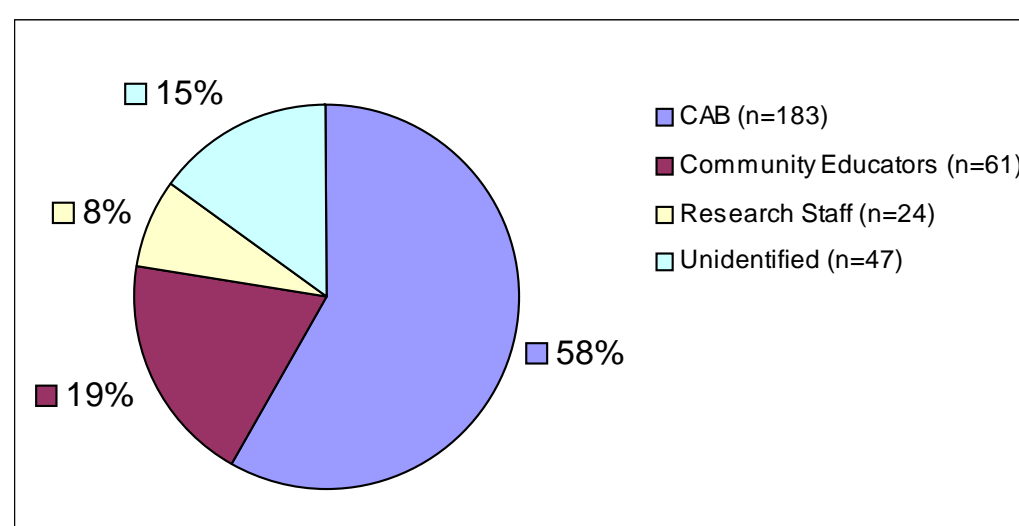
## Survey Design Process and Structure

- Review of HPTN guidelines on community participation
- Literature review on community based research
- Formation of the Community Indicators Committee – comprised of CAB members, Community Educators, research staff, and administrative staff
- Group review and critique with CAB members, Community Educators, and research staff from the Americas, Africa, and Eurasia regional working groups
- Through this iterative process, we created a 31-item questionnaire that divided community participation into six domains: CAB Function, CAB Process, Research Team Involvement, Research Design and Process, Ethical Issues, and Outcomes.

## Respondents and Survey Completion

- The survey was completed by research staff and CAB members through one of two means:
  - *Individual responses* – individuals read and responded to the questions on their own noting any questions or issues that they would like to discuss with the CAB/research staff group.
  - *Consensus method* – CAB/research staff collectively read, discussed the questions, and responded to the questions with answers agreed upon on as a group.
- Twenty-two out of the total twenty-six sites participated in the survey evaluation.
- 315 responses were received from the following types of respondents: 183 CAB Members, 61 Community Educators, 24 Research Staff, and 47 unidentified respondents.

Figure 1: Respondent Categories



## Results

- Figure 2 depicts the mean scores from all respondents for each domain.
- Overall, the results are supportive of community participation, with all mean scores above 75% in the direction of greater community partnership.
- Respondents rated sites comparatively well on ethical issues, such as ensuring community understanding of the risks and benefits of research involvement (mean score 85%), and on how the research team interacts and communicates with the CAB (mean score 87%).
- Sites performed lowest on communicating findings and research results to communities (mean score 77%).
- Figure 3 depicts the mean scores for each domain for the Research Staff and CAB member respondent categories. The greatest differences were observed in the CAB Function domain (difference score of 10%) and Research Team domain (difference score of 6%).

Figure 2: Mean Domain Scores of Community Partnership Across all HPTN sites (N=315)

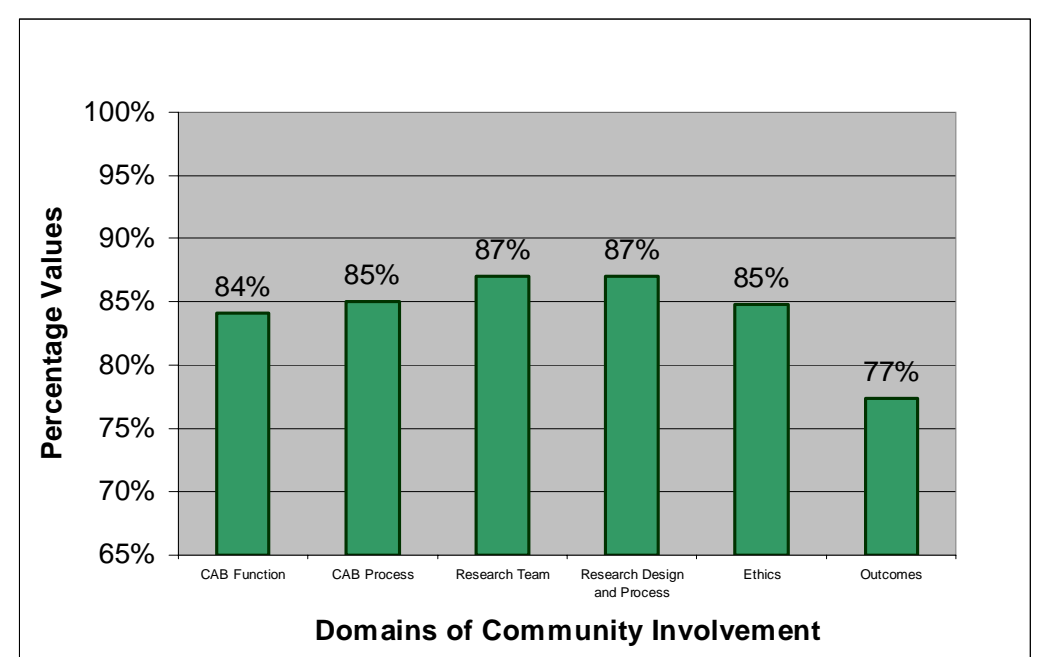
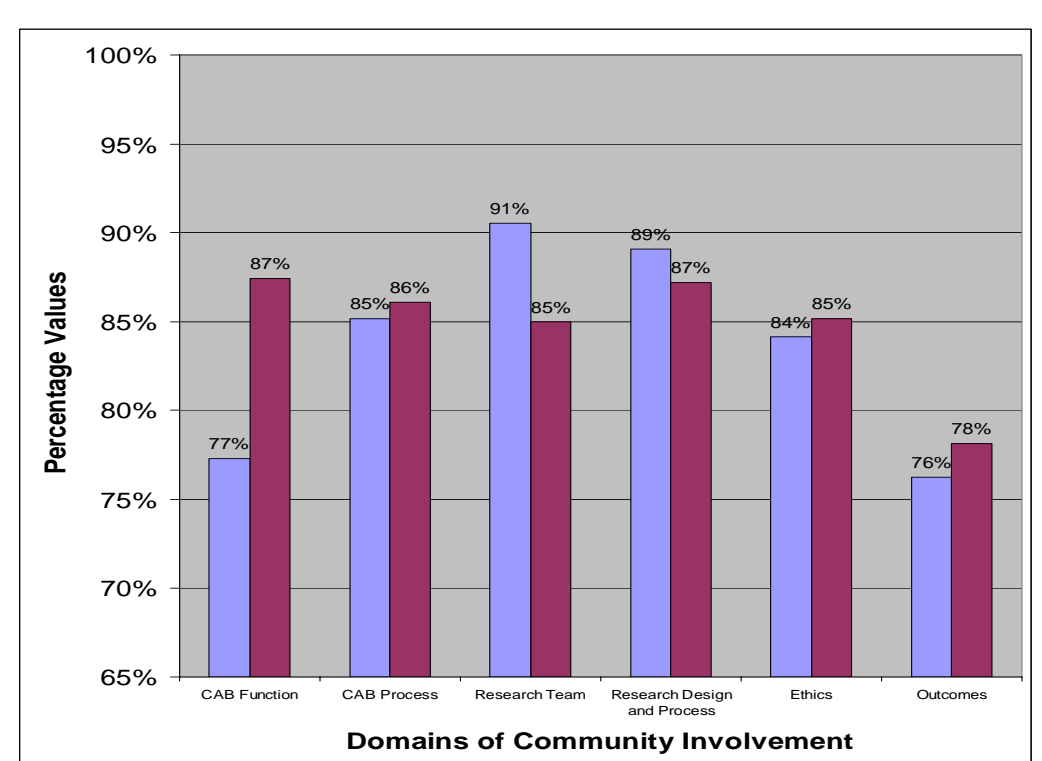


Figure 3: Domain Means for Research Staff (N=85) and CAB (N=183) Respondents



## Analysis and Applications of Findings

- Survey results served as a catalyst for discussion on the status and quality of research-community partnership.
- Site-level discussions identified the causes of the observed scores, ways to maintain high performing areas, and means to improve low-performing areas.
- Common themes raised by the survey included the following:
  - diversity of community representation and determining which communities are important to involve in the consultative process
  - the quality and improvement of communication between researchers and host communities
  - identifying strategies for concluding studies and disseminating findings
  - adequate community involvement in the development of new studies
  - reconciling differences between research staff and CAB members' perspectives.
- Research staff and trial managers used the survey data to identify technical assistance needs to enhance community partnership. In response to survey findings, trainings are planned in the following areas: roles and responsibilities of CABs for new CAB members; research ethics for community representatives; how to read a protocol; and advocacy skills.

## Lessons Learned

- Monitoring and evaluation of community partnership activities along with analytic discussions of the results should be performed.
- Such assessments can identify action steps so that research is responsive to community needs and the full potential of researcher-community partnership is achieved.
- Care must be taken to avoid creating perceptions of punitive repercussions from evaluations of this nature. Practitioners should be mindful of participants' reactions and emphasize the constructive nature of the assessment process.

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