

Community Working Group Strategic Planning Report Washington DC, 18-19 February 2002

1. Executive Summary

Overview

The HPTN Community Working Group (CWG) held its strategic planning meeting February 18-19, 2002 in Washington, DC. As a result, the group identified the need to move from an advisory / consultative function to a true partnership / collaboration role. There was consensus by the group that this model is a continuum, and that some sites may be at different places. Having reached this agreement, the group established the following goals for the CWG:

- **To increase understanding of community collaboration in HIV prevention research.**
- **To develop community capacity within HPTN sites to participate in research collaboration.**
- **To assure that all research conducted within the HPTN is done in collaborative partnership with the community by integrating community perspectives.**

The group worked to identify objectives and strategies for each of the goals that were presented to the HPTN Executive Committee for response. Additional work was done to propose a new streamlined structure for the CWG that reflects regional working groups. The Executive Committee endorsed the report and charged the group to identify action steps and make budgetary recommendations.

Next Steps

The following items were identified as action items to address the question, "How do we move from process to action?"

- Re-visit the objectives and strategies to finalize the CWG strategic plan
- Establish measures of shifts along the consultation / partnership continuum
- Address the reorganization needs of the CWG to reflect a regional focus
- Identify next steps for the full HPTN to support community partnerships throughout the network at all levels of the research process

2. Context Leading Up to Strategic Planning Process

From its inception, the HIV Prevention Trials Network has built into its language and processes the value of developing and supporting community participation at all levels of the research. By necessity, the Network needed to start somewhere and created guidance to describe how this would be done. A Community Working Group (CWG) was created to address Network issues of community participation, and every HIV Prevention Trial Unit (or site) would have a locally identified process for community involvement and consultation regarding the research to be conducted. To assist with this process at the sites and in the Network, the core management of the HPTN created the Community Involvement Program that provided staffing and resources.

In the initial implementation of these community participation processes, the broadly defined goals were stated in the CWG's mission statement:

The mission of the Community Working Group of the HIV Prevention Trials Network (HPTN) is to inform and help guide the development of a community-centered, relevant, utilitarian and ethical research agenda. Through the formulation of recommendations and strategies towards this goal, the CWG seeks to be the bridge between the at-risk individual, the communities they live in and the social context of this risk and the deliberative processes of the HPTN. As the liaison for the community the CWG proactively identifies challenges, translates needs and provides the formalized mechanism for dialogue that will guarantee high quality research aimed at effectively reducing the number of new HIV infections.

Under this mission, the CWG and the Network created a system to initially support integrating community participation into the HIV prevention research. Under the leadership of Janet Frohlich (South Africa) and Steve Morin (United States), the CWG Co-Chairs identified the need for restructuring the CWG's mission in a way that reflected the experiences of the communities involved in the process. As a result, the CWG leadership team (Co-chairs and HPTN staff) re-crafted the mission statement into workable goals and initiated the development of a strategic planning process.

The re-crafted goals identified for the CWG were:

- 1) To increase understanding of community consultation in HIV prevention research.**
- 2) To develop community capacity within HPTN sites to participate in research consultation.**
- 3) To assure that all research conducted within the HPTN integrates community perspectives.**

3. Strategic Planning Process

The Community Working Group's leadership team decided a strategic planning process was necessary to clarify how the group conducts its business while supporting community involvement in HIV prevention research at all levels of the HPTN. To assist with the process, an outside consultant was identified to help in the process. Lydia Ogden from the Centers for Disease Control and Prevention agreed to assist the CWG leadership with her experience facilitating organizational strategic planning processes.

The basis of the strategic planning process was designed to take place at the annual face-to-face meeting of the CWG. In order to provide a context for the work to be done, presentations to provide background information were conducted. The following presentations were made in introduction to and in explanation of the strategic planning process:

- Information about the HPTN and CWG presented by Janet Frohlich (Appendix X)

- Previous community involvement strategies that have worked presented by Ron Strauss (Appendix X)
- Summary of information about the CWG's process in the HPTN from two sources:
 - Formal rapid assessment process conducted in the HPTN presented by Steve Morin and Anne Richards (Appendix X)
 - Observations of cross cutting issues from the Africa and Regional Community Trainings and CWG conference calls presented by Janet Frohlich (Appendix X)
- Overview of the Strategic Planning Process presented by Lydia Ogden, Presenter (Appendix X)

The group was charged to look optimistically but realistically about all options for the CWG, sites and the Network regardless of constraints of budget or organizational/political structures. The organizers believed that this broader perspective would be best for identifying the optimum structure of the strategic plan understanding that the CWG leadership and the Network would be responsible for identifying ways to address the objectives identified.

At the meeting, the CWG broke into three groups to address each of the three CWG goals and identified objectives and strategies to support each of the goals.

Each group worked with their assigned goal to identify objectives and strategies to increase understanding about the goal and how to achieve it. The groups worked to sift through the different ideas, identified if they were realistic and put them into linear order. To help the process along, each group had two co-chairs and a facilitator.

The two co-chairs (one from an international site and the other from a US site) helped provide a Network context and background information to the discussions. Co-chairs were identified based on their having a level of experience with the goal for their group. Their role was to help create and sustain discussion in order to identify and prioritize objectives and strategies to meet their group's CWG goal.

The facilitator helped ensure the process moved along, served as note-taker, and acted as a helper to the co-chair regarding process and summarization. Their role was less directive regarding content and more supportive of the process.

The groups were charged to sift through their objectives and strategies to identify the building block concepts that make best sense to meet their goal, and then prioritize them. Participants were informed that not all identified objectives and strategies may be feasible given available resources, but it was necessary to identify the structures and activities that would give the best model to target.

Each of the groups reported back to the full group in order to review the work accomplished and identify cross cutting themes and challenges/restraints. Once the group identified these themes, a prioritization process was conducted to identify the key themes for the purposes of reporting and taking action.

A quick review of the process and results was compiled into a presentation that was given by Janet Frohlich and Steve Morin to the HPTN Executive Committee the day after the strategic planning process was conducted. It was decided that a final report of the results of the strategic planning process would be put together into a report to be given directly to the Executive Committee.

{Endorsed by the EC, Directly endorsed by ~ EC took action to endorse the report of the CWG, then gave us the charge to come up with the budget and action steps to do the work. Discretionary funds would be available to continue with this. Other funding needs to be investigated and pursued – CDC’s domestic \$\$, NIH directly, AID country specific proposals, cooperation of the government could ask for Global AIDS Funds, Lydia Ogden – can try to get the \$\$ out from there}

4. Clarification of the Goals

In preparation for conducting the strategic planning process, members at the CWG meeting requested clarification about what was meant by a number of the words being used in the three goals, specifically requesting clarification about what was meant by “consultation.”

A key outcome of full group discussion identified that the aim of community involvement in HPTN research at both site and network levels was to move from a community consultation model to true collaboration and partnership model, or from a symbolic and advisory role to authentic community collaboration and participation in decision-making about the research. Partnership was equated with shared power, while consultation implied little opportunity to make decisions and initiate action.

Participants acknowledged that this was a continuum, and that some sites had not yet even achieved community consultation. This model is akin to health planner Sherry Arnstein’s “ladder of participation.”

“The bottom rungs of the ladder were two forms of ‘nonparticipation’ – therapy and manipulation. In the middle were several ‘degrees of tokenism’ – placation, consultation, and informing – through which community members were heard and might have a voice but did not necessarily have their input heeded. Finally, the top rungs of the ladder were three degrees of “citizen power” – partnership. Delegated power, and true citizen power.”

(From Meredith Minkler, 1999. Community Organizing and Community Building for Health. Rutgers University Press p. 127)

As a result of the full group discussion, it was decided that each group would be responsible for reviewing the wording of their goal and to make changes to reflect the understanding of partnership and collaboration as described above.

5. Group Work Results

The next section describes the results of each of the small groups' work, with the new articulation of the goals. Each group conducted their process in a slightly different manner and is reflected in the way their results are presented.

Group 1: To increase understanding of community collaboration in HIV prevention research.

This group spelled out ten (10) key objectives. For each of the objectives, additional activities were brainstormed and then prioritized by placing red dots next to each activity. The numbers behind each activity indicate the number of votes.

1. Expectations for training and accountability of investigators and site staff. (9)
 - Require investigators to go into the field
 - PIs should attend periodic CAB meetings, and if not, why? (1)
 - Conduct workshops for investigators (ex. on social needs) (1)
 - Require regular research updates by PI to CAB and staff (3)
 - Link funding criteria to completed process evaluation between site staff and CAB (6)
 - Think about trial participants' language, economic conditions, informed consent (1)

2. Conduct community assessments before the grant is written, after funding is awarded and continued monitoring. (9)
 - Conduct annual / ongoing consensus meetings that include presentation of epidemiological profile / secondary data, existing interventions. Include target populations, NGOs, political and religious institutions, CAB and site staff (10)

3. Build rapport with the community and return findings to the community. (5)
 - Work with the community from the beginning; assess needs (7)
 - Deals with questions about benefits of research to the community
 - Use the assessment to know how to reach the community; link with social science (2)
 - Plan to build rapport through community outreach (5)
 - Plan and secure funds to return findings to community as part of the grant application, using assessment (3)

4. Educate the community using peer educators, including PLWAs, and inform people of the benefits and risks of research on their lives.
 - Work with outreach groups, nodal and existing agencies (7)
 - Link with outreach efforts – use community health workers
 - Point to some successful products of biomedical research, using media campaigns, street plays, etc. (3)
 - Look at historic events to serve as discussion focal points
 - Develop curricula for schools (1)
 - Include personal models (1)

5. Build incentives for investigators to do community-based research.
 - Stimulate a journal for international CBR within the HPTN (2)
 - Award for site that most demonstrates effective community involvement (5)
 - Identify grant incentives
 - Use existing media
 - Work with government funding agencies and private / public universities to institute changes (4)
 - Present at national and international conferences

6. Repair the damage from past mistakes, knowing that all damage cannot be repaired. Complete honesty is critical. (5)
 - Tell the truth – the whole story; linked with community-based ethics training and continuing education (11)
 - Ongoing clarification of commitments
 - Make sure people understand it's research and not treatment (1)
 - Explain the levels of research
 - Define placebo and risks
 - Make sure the products are useful and made available
 - Encourage interaction – engage in overall health and wellness

7. Informing people why investigators are doing what they do and why in my community.
 - (Merge with objectives 3. and 4.)

8. Evaluate the political, legal, cultural environment, including stigma, to maximize community collaboration and informed consent.
 - (Merge with objective 2.)

9. Don't only focus on primary prevention, but include efforts to involve PLWAs.
 - Mass education on differences between primary and secondary prevention; link with existing organizations who have models of secondary prevention that are working (7)
 - Work with existing organizations to improve treatment opportunities, counseling and support services (ex. using peer health workers)
 - Focus on caregivers (1)
 - Develop an awareness of all costs and availability of treatment

10. Work with the media, political and religious institutions and schools to achieve community education.
 - (Merge with 3. and 4.)

From these, **five priority items** were identified:

1. Conduct ongoing community assessments, utilizing process evaluation and existing research.
2. Repair the damage, using the media and one on one. Tell the truth.
3. Work with existing agencies and outreach groups to educate communities using personal models.
4. Consider a HPTN award for best site community involvement.

5. Include secondary prevention in the HPTN focus, using mass education to demonstrate successful secondary prevention models.

Group 2: To develop community capacity within HPTN sites to participate in research collaboration.

This group spelled out four (4) key issues. For each of the issues, additional activities were brainstormed and then prioritized by placing red dots next to each activity. The numbers behind each activity indicate the number of votes.

1. Resources: Human and Material

- Access to and participation in budget: transparency, disclosure (18)
- Adequate budget to ensure community awareness and education (16)
- Enough CAB members to serve the community; orientation and training (5)
- Adequate budget for infrastructure: space, computers, phones(4)

2. Training / Mentoring

- “101” courses: introductory courses on HP TN, HIV, science, clinical trials, ethics (13)
- Appreciation of community involvement: importance of past experiences, activist success stories; to empower the CAB (6)
- Create forum for PIs and CABs to talk (4)
- Set up an exchange program, ie. buddy system: sharing of experiences and problem-solving (4)
- How to do strategic planning (4)
- Community interactions: providing and receiving feedback (2)
- How to run meetings and conference calls; criteria for participation
- Use of technology (1)
- Developing teamwork capacities
- How to identify stakeholders
- How to develop CAB mission statement
- How to be a community educator

3. Team Building / Partnerships (11)

- Building the “site team”
- Identification of other agencies, and then collaborate (11)
- Establish communication system for CABs; reporting (5)
- Defining roles and responsibilities (4)
- Retreats – off-site, facilitated
- Survey CAB re. needs and priorities
- CAB brochure

4. Cross-cutting Issues

- U.S. / international
- Definition of terms

Group 3: To assure that all research conducted within the HPTN is done in collaborative partnership with the community by integrating community perspectives.

This group spelled out three (3) key objectives. For each objective, additional strategies and action steps were brainstormed and then prioritized in order of their presentation.

1. Identify measures for collaborative community involvement.

Strategies:

- Assess needs: conduct situation analysis of community (focus groups, survey); document collaboration (reports, interviews)
- Develop and implement capacity development program
- Monitor – through qualitative and quantitative measures: random checks on community involvement; recruitment and retention
- Create a communications mechanism to promote community feedback: CAB letter supporting protocol proceedings

2. Ensure joint decision-making in planning, implementation, evaluation, and reporting of results.

Strategies:

- Create skills-building training programs to empower community members to participate in the network: increase knowledge and leadership skills
- Develop site-specific plans for community involvement
- Include community members at all levels of the network to reflect the multicultural nature of the HPTN: CABs, scientific working groups, HPTN committees: develop global capacity development plan for SWGs and CWG
- Assess the current HPTN structure and whether it supports community participation: determine the need for regional boards
- Create skills-building training for site and network personnel to increase understanding of community involvement

3. Make the HPTN more multicultural / multiracial.

Strategies:

- Create HPTN operational structures that increase participation from sites : Africa, Asia, Eastern Europe, South America
- Recruit, hire and train multicultural and multiracial persons at all levels of the network
- Document multicultural / multiracial contributions to the HPTN
- Sensitize PIs, staff, EC, SWGs and CABs on community involvement
- Review structure of the HPTN

6. Common Themes

A number of **cross cutting issues, challenges and restraints** emerged repeatedly during the strategic planning process in both the goal-focused and regional small groups. These issues echo what we knew from discussions within the Community and Ethics Working Groups, Africa and Asia regional trainings, and feedback from sites regarding community participation in the research agenda.

Cross Cutting Issues include:

- Training
- Budget – adequate resources
- Community assessments
- Communication
- Increase understanding of collaboration / partnership
- Multicultural / racial, gender and social issues
- Counseling to HIV infected and affected family members

Conversely, Cross Cutting Challenges and Restraints include:

- Constraints/limitations on budget, human resources, time, etc.
- Weak commitment to the community
- Diversity and multiculturalism as a challenge across many different site and local definitions.
- Lack of clarity of roles, responsibilities and expectations
- Lack of community feedback
- Lack of science on community research

Previously identified issues and themes include:

1. Building the community / researcher partnership
2. Participation in scientific agenda
3. Structure & activities of the CWG
4. Technical assistance & support
5. Community participation informs sound ethics

1. Building Community/Researcher Partnership

- Define the broad definition of community when working with both rural and urban sites – direct & indirect stakeholders
- When do we begin the community involvement processes?
- Community education program needs to develop parallel to the scientific protocol development
- Community participation is a consultative process to facilitate two-way exchange
- How do we shift from tokenism to effective community partnership
- What is the HPTN understanding of “partnership”?

2. Participation in Scientific Agenda

- Representation of community in protocol development needs to be supported and initiated in all protocols
- Ability to read & understand protocol
 - Increase CAB exchange at regional level
 - Attending CAB meeting is not enough
- When do we engage the community in protocol development
- Delegate Community Liaison to move the process forward

- When does the Community Educator get appointed & the community education programme begin?
- Include timelines in the guidance documents regarding when to bring communities on board around protocol issues and documentation
- How to sustain and coordinate community and site activities (to ensure recruitment, retention, and care/support for enrolled and non-enrolled participants)

3. Structure & Activities of CWG

- Examine the management of the CWG
- More regional/site collaboration for communities and research levels ~ needs to be regional and multi-site reinforcement
- How do we reinforce regional & site collaboration at the community level?
 - Divide calls to parallel scientific working groups calls so they are protocol specific
 - Arrange calls by region
- Lack of communication between CABs
- Being open to alternative structures of the CAB to meet the local needs

4. Technical Assistance & Support

- Each site has a community educator to build the bridge and drive the community involvement process
- General resources, staffing, facilities for counseling
- Identify and plan for appropriate budgeting
- Identify methods to help sustain and support the advisory volunteers
- Need for targeted CAB training
 - Role and responsibilities of CAB not clear
- Translate presentation materials in advance of workshop to allow for greater participation
- Post the Community Involvement Workplans on the website to become a resource for other sites
- How do the sites ensure that they have appropriate budgets to sustain the coordination of activities?

5. Community Participation Informs Sound Ethics

- Informed consent process has had the greatest input
- Community participation is not only about reviewing informed consent
- How do we ensure mechanisms are in place for those potential participants who are excluded from trials because of their HIV status, and what kind of referral systems will be in place?
- Advise and implement community ethics training of local IRBs
- Address in-country research issues such as adequate experienced counseling resources and services (burden is presently on the sites)

Report Appendices

- “Strategic Planning: Community Working Group Overview” – Janet Frohlich (PowerPoint presentation)
- “Community Consultation: Overview” – Ron Strauss (PowerPoint presentation)
- “Rapid Assessment Findings” – Steve Morin and Anne Richards (PowerPoint presentation)
- “HPTN Cross-cutting Community Themes” – Janet Frohlich (PowerPoint presentation)
- “Introduction to Strategic Planning” – Lydia Ogden (PowerPoint presentation)
- Strategic Planning group work / results (Word document)
- Original suggestion for model of CWG restructuring (Word document)
- CWG Cross Cutting Issues Prioritizations (PowerPoint presentation)
- Regional reports / strengths and challenges (Word document)