

The HPTN Community Working Group (CWG)— Ensuring Community Involvement in HIV Prevention Research

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Introduction

Clinical trials for the advancement of HIV prevention are most likely to succeed when all stakeholders regard the research as a collaborative process. Researchers and community members bring unique and important contributions to the research through a process of knowledge exchange. The challenge is to ensure that the best interests of the study participants' community are being considered by taking into account the community's context, needs and culture. The HPTN Community Working Group (CWG) is committed to increasing community partnerships and collaborations in HIV prevention research; developing community capacity to participate in research; and ensuring that all research integrates community and cultural perspectives.

The CWG facilitates community involvement by building effective partnerships, including relevant stakeholders, advocating for adequate resources to ensure appropriate community preparation and education, informing and advising the HPTN Executive Committee (EC) on emerging issues of concern, and ensuring community representation and participation on all HPTN working teams. The CWG has implemented a community involvement strategy at the site/HPTU, regional and network leadership levels that has informed sound research ethics. The CWG facilitates dialogue between the community and researchers and works with the scientific team to implement high-quality HIV prevention research.

Finding Direction

To assist the community involvement process at the site/HPTU, the CWG and the HPTN CORE community program developed the community involvement program. The first annual CWG face-to-face meeting was conducted on October 25, 2000, after the full HPTN meeting in Washington, DC. Key points identified at this meeting included the following: an expressed interest in creating regional linkages; a need to ensure adequate representation by international sites; support and sufficient budget to ensure adequate community involvement in HPTN research, and an acknowledgment

that the development of the community involvement processes takes time and should run in parallel with the development of the science research agenda.

The CWG and the CORE community program staff decided that a strategic planning process was necessary to clarify how the CWG should conduct its business while supporting community involvement in HIV prevention research at all levels of the HPTN. A strategic planning workshop was held at the CWG annual meeting in February 2002, and new goals were identified for the CWG:

- To increase understanding of community consultation in HIV prevention research
- To develop community capacity within HPTN sites to participate in research consultation
- To ensure that all research conducted within the HPTN integrates community perspectives into that research

After recrafting the goals of the CWG, the group restructured the organization of community involvement within the HPTN, moved from a consultation model to a partnership model, and established Regional Working Groups (RWGs).

Structure and Membership of the CWG

Originally the CWG had 20-25 members. As an outcome of the 2002 CWG strategic planning meeting, the CWG was restructured to ensure relevant stakeholder representation. The CWG currently has up to 15 members (Figure 1).

- Two CWG co-chairs — one international and one from the United States
- Six regional working group chairs — two from each of the RWGs (Africa, Americas and Eurasia)
- Two EC representatives (appointed by the EC chair)
- Two CAB members
- Three to five *ex officio* members representing social sciences, legal concerns, and ethics.

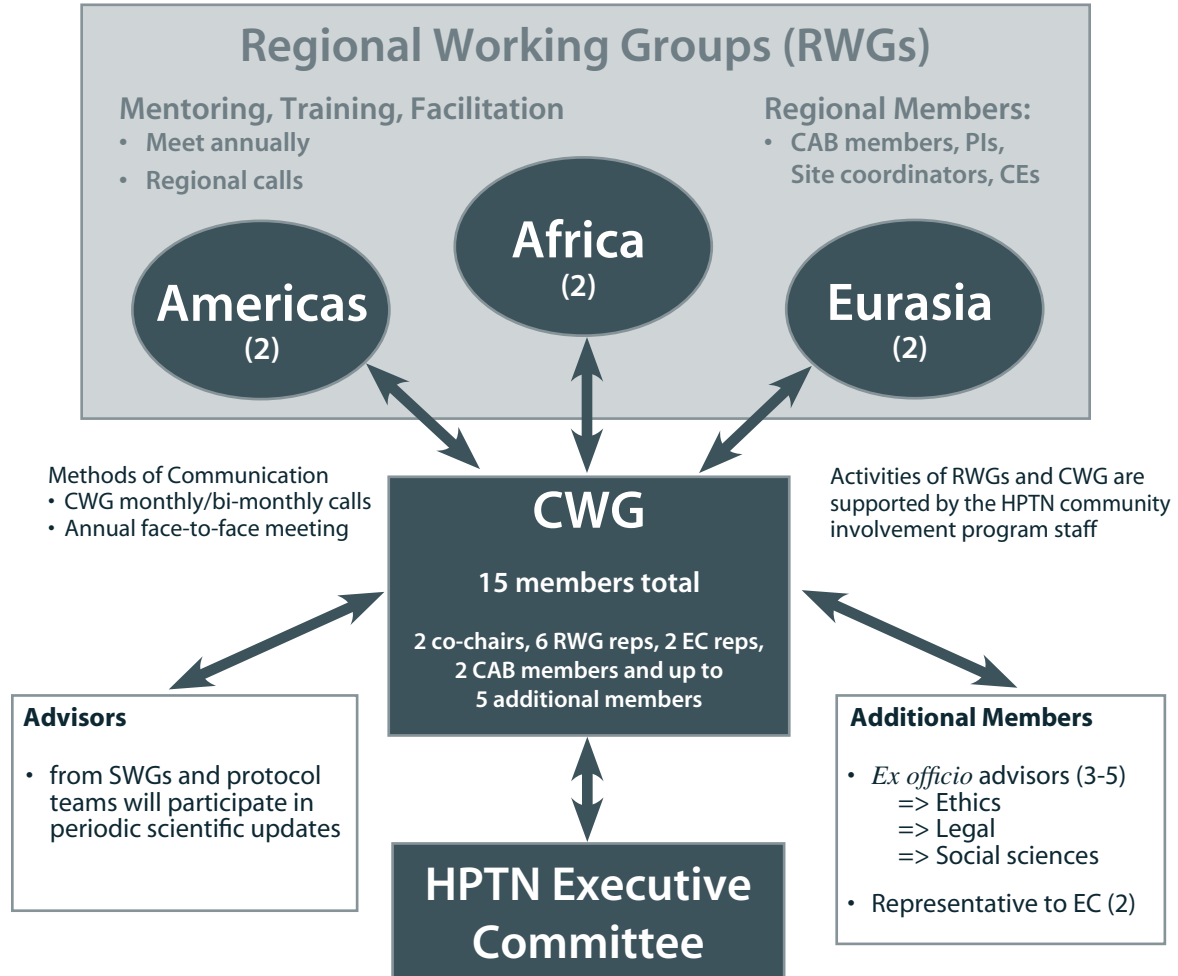
The CWG meets regularly via conference calls and, at a minimum, annually at a face-to-face meeting that usually coincides with the HPTN Annual Meeting. Regional CWG meetings are held annually, and monthly conference calls are facilitated by the HPTN CORE community program. The CWG and regional CWG meetings provide a forum for identifying new and emerging issues, promoting community capacity building, monitoring community involvement, receiving feedback from sites/HPTU and scientific updates from protocol chairs, reviewing network leadership structures, and discussing crosscutting community involvement issues in HIV prevention research. A critical component of these meetings has been the exchange of lessons learned among site/HPTU representatives, CABS, community educators, the CWG and HPTN CORE community program.

The CWG is active in the HPTN both as a working group and with its representation in the HPTN governing processes. The EC representatives that serve as the CWG liaisons ensure appropriate representation at the network leadership level. In addition, the CWG co-chairs report to the EC at the annual face-to-face meeting. The CORE community program staff provide technical and logistical support for the CWG.

Figure 1. The Community Working Group (CWG) Structure

Restructured at the Strategic Planning Meeting, Washington, DC 2002

GOALS: advocate, empower, take action, build capacity, provide technical assistance



The CWG Community Partnership Model

From its inception, the HPTN has built into its language and processes the value of developing and supporting community involvement at all levels of research. As an outcome of the CWG strategic planning process, community involvement has moved from a community consultation model to a model of true collaboration and partnership, and from tokenistic to authentic community participation in decision-making. “Power” is equated with shared power while “consultation” implies little opportunity to make decisions and initiate action. The CWG acknowledges that the community partnership model is constantly evolving (Figure 2).

This partnership 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.”

Figure 2. The CWG Community Partnership Model



Through a partnership model, the CWG has moved beyond an advisory role on procedural community consultation to developing successful community partnerships. It has achieved this through representation on HPTN leadership, participation in the ethics working group, technical assistance to sites/HPTU, establishment of RWGs and coordination of community capacity building.

Establishing Regional Working Groups

Another outcome of the strategic planning process was the establishment of three RWGs, in Africa, the Americas and Eurasia. Seven regional workshops have been held to establish a community participation and education strategy for ensuring active participation at local, regional and international levels within the HPTN. Topics in these workshops included:

- Background and structure of the HPTN
- Phases of clinical trials
- Ethical issues

- Protocol development
- The process of community participation in the HPTN
- How to build and maintain a successful CAB
- Roles and responsibilities of CAB members
- Developing and implementing a successful community education and participation program
- Outlines for site-specific community action plans
- Strategies for translating research and study-specific information into local languages and appropriate levels of literacy
- Development of dissemination strategies for completed studies
- Lessons learned regarding stigma reduction and community participation in international HIV prevention clinical trials.

“Community participation is ethics in action!”

— *Quarraisha Abdool Karim,*
HPTN Executive Committee
Community Representative

Anecdotal reports from the field indicate that participants have been able to apply new knowledge and skills in their local settings. For example, training modules on stigma reduction have been easily replicated and effective outreach activities to increase male involvement in HPTN research have been adopted by newer sites.

The Emerging Role of CABS

While most sites/HPTUs have established CABS to facilitate dialogue with the community, their effectiveness in contributing to the scientific agenda had not been assessed. A number of HPTN sites participated in a rapid assessment to gain a better understanding of how community advisory structures could be used to improve the quality of HIV prevention trials (Morin et al. 2003). CABS viewed their role as a bridge between the research team and trial participants and further identified the need for objective ways to assess community participation in the research process. Through a consultative process, indicators of community involvement were identified. Six domains for the Community Indicator Survey were identified (CAB function, CAB process, research team involvement, research design, ethical issues, outcome, and feedback to the community). This survey was field-tested, evaluated and implemented, and has been used by other HIV research networks to evaluate their community programs. Further contributions of CABS to the HPTN scientific agenda have been achieved through early discussion of the appropriateness of the proposed trial, review of informed consent (IC) and IC processes, guidance on outreach and retention methodology, and selection of community representatives to HPTN RWGs and meetings.

Conclusion

While the CWG has garnered substantial experience through HIVNET and the HPTN, many challenges remain. The process of managing community involvement needs to be coordinated through an established community of key stakeholders, who will create a partnership between the researchers and the communities in which they work. Community involvement must be integrated into all levels of HIV prevention research, including concept development, implementation, and dissemination of research findings. There is a need to increase autonomy and provide sufficient resources to support local community involvement. There must be adequate community

representation on protocol/study teams. Finally, a community-specific research agenda that links scientific outcomes with indicators of successful community participation should be developed.

Reference

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Acknowledgments

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