

Foreword

In the two decades that the world has been fighting the global HIV/AIDS pandemic, community has been ever present. In the late 1970s, the virus was making its way into communities all over the world. In the developing world, however, the impact of AIDS was masked by other endemic diseases that contributed to morbidity and mortality. In the early 1980s, when the epidemic's impact was becoming evident in the United States, the gay community led the prevention efforts in an attempt to protect themselves from a killer that still had no name. Later, when the virus was identified and treatments were being developed, men and women representing the ever-growing community of infected and affected individuals spoke out against the barriers that kept them from participating in cutting edge research and access to life-prolonging treatments. Now, in the age where we have realized that we are all affected by HIV/AIDS (whether we are infected or not), men and women all over the world speak out for their communities in an effort to fight a growing pandemic that has already claimed millions. These men and women represent those who are advantaged and disadvantaged. They represent every race, creed, and color. They represent those who abstain from sex and those who do not. They represent those who are both held in esteem by our societies and those who are stigmatized. They represent those who can shout out and those whose voices cannot yet be heard.

These men and women represent all of us as members of the global community.

To many communities, the concept of research is a confusing one. While scientific method focuses on logical methodology and the objectivity of data, research often takes place in contexts where the reality of life is anything but logical or objective. The truth of science is not necessarily the truth of the community. Thus, by default, there is often an impasse in terms of communities understanding and/or supporting the goals of research, even research that has the potential to save the lives of those most at risk.

Conversely, the concept of community is often very confusing for researchers. Most researchers are focused on the nuts and bolts of the science rather than on the perceptions that the community has of the science. Researchers receive extensive training in how to analyze their data, not how to effectively dialogue with local and national stakeholders. To that end, well-intentioned researchers are often put in the very difficult position of needing to learn these skills as they go along, in hopes that their attempts to “do the right thing” will be understood and acknowledged.

That being said, the fortunate fact is that the two worlds of community and research are moving closer and closer together. For many researchers, the perception of community has evolved from “the place where we get study subjects” to “the people with whom we build research partnerships so we all have a better understanding of what is being done.” For community members, researchers have become less the “untouchable ivory tower scientists” and more “potential partners who can help us make our community a healthier place.” These are important transitions, as the shift in perspective allows each group to see the other not as an adversary, but as collaborating partner. There will undoubtedly be obstacles in the course of this partnership. For some, it will be difficult to address the most critical issues because of political sensitivities, restrictive government policies, or group or community loyalties. For others, the greatest challenge will be rooted in the difficulty that most individuals and organizations have with self-evaluation and the acceptance of constructive criticism.

This document is an important initial step in working to facilitate and strengthen the community-researcher dialogue that is crucial to HIV prevention research. As a member of the HIV Prevention Trials Network, I am proud of the accomplishments that have been made to facilitate greater involvement of community in our research. It is my hope that this document can serve as a tool for broadening

our understanding of the importance of the community's role in international research and inspiring us to overcome the obstacles that hinder fruitful partnerships. At the end of the day, the obstacles faced are worth enduring for the sake of achieving our shared greater goals: individuals who are empowered to protect themselves from HIV infection, families who can access the HIV care and treatment they need, communities that can accept infected and affected persons without imposing stigma, and — eventually — a world without AIDS.

A handwritten signature in black ink, appearing to read 'Monica S. Ruiz', with a long horizontal flourish extending to the right.

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Introduction

The HIV Prevention Trials Network (HPTN) is a worldwide collaborative clinical trials network that develops and tests the safety and efficacy of primarily nonvaccine interventions designed to prevent the transmission of HIV. Established in 1999 by the Division of AIDS (DAIDS) of the National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health (NIH), the HPTN carries out its mission through a strong network of expert scientists and investigators from more than two dozen international sites partnered with a leadership group comprised of three U.S.-based institutions.

Many scientists and policy-makers have come to realize that HIV/AIDS clinical trials and other prevention interventions are most likely to succeed if community members are closely involved in the research process from inception through information dissemination. Community needs and opinions should be considered in setting prevention research priorities, designing the protocol, developing recruitment and follow-up plans, determining appropriate incentives for trial volunteers, considering informed consent issues, and developing risk-reduction interventions.

This sort of collaboration takes commitment from researchers to provide training, partnering, and mentoring, as well as from the community itself to listen, learn, participate in workshops and attend meetings. This book shares examples of diverse community participation strategies that have been implemented in the last several years. We must continue to improve and strive for full integration of the community in all levels of the research process.

History has shown that successful HIV research projects have been significantly aided by active engagement with the community where the research is conducted. In addition to the many scientific articles that will be published from the data obtained through the HPTN's HIV prevention research, we recognize that it is equally important to document the diverse array of activities that have been carried out to promote community involvement and collaboration in research and to identify some of the main lessons learned.

This document has the following objectives:

- To relate experiences of community involvement and collaboration in HIV prevention research of the HPTN
- To achieve a deeper understanding of the role played by community educators and community advisory boards (CABs) in HIV prevention research
- To use these lessons to strengthen and refine community involvement strategies at study sites as well as within the HPTN CORE, community working groups, regional working groups and future structures
- To contribute to the knowledge base on community involvement in international research

Our target audience for this document consists of:

- Community advisory board members and community educators
- HPTN members and other clinical trial networks
- Nongovernmental and community-based organizations
- Academics
- Journalists

This document is divided into two parts. Part 1 starts with a literature review on the subject of community involvement in HIV prevention research. Next is an overview of the HPTN's Community Working Group, followed by an article by the HPTN CORE Community Program, some of the main challenges the program encountered and lessons learned. In Part 2, HPTN sites were invited to submit articles on their efforts to

facilitate community involvement at a local level. There are a total of nine articles, one each from Chiang Mai, Thailand; Pune and Chennai, India; Dar es Salaam, Tanzania; Kampala, Uganda; Lusaka, Zambia; Harare, Zimbabwe; Lima, Peru; and Boston, Massachusetts, United States. Finally, we have included a consolidated conclusions and recommendations section, with additional input from HPTN sites not represented in this document. The appendix presents a matrix that gives an overview of training workshops provided between 2001 and 2005.

These articles contain a truly rich amount of information on experiences, challenges, insights and lessons on how communities can be meaningfully involved in research working with diverse populations in diverse contexts. The reader may learn lessons beyond those intended by the authors, because information that one person takes for granted as common knowledge may be innovative and original to someone else. May this document contribute to continued learning, expanding and strengthening of community involvement efforts in research around the world.

