

# Literature Review on Community Participation in HIV/AIDS Prevention Research

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## Introduction

The burgeoning of the HIV/AIDS crisis over the past 25 years has mobilized the world to consider the issue of public health in an entirely new light. The urgency of preventing the spread of a fatal virus, and the highly personal nature of HIV transmission, have made collaboration at all levels of society imperative. Despite unprecedented action by communities, governments and researchers in many parts of the world, more than 20 million people have died from HIV/AIDS (UNAIDS, July 2004). According to the Joint United Nations Programme on HIV/AIDS, by December 2005, the largest number of people since the HIV pandemic began were living with the virus: more than 40 million, including close to 13,500 new infections per day in 2005 (UNAIDS, December 2005). Clearly, the need for widespread dissemination of best practices combined with promising and innovative strategies to prevent the further spread of HIV has lost none of its urgency.

Community involvement in research activities has emerged as one important and necessary strategy for advancing HIV prevention efforts, but defining “community involvement” and implementing it successfully often present numerous challenges. Community involvement may give rise to a wide spectrum of social and ethical questions, especially when the concerned communities include people who are disadvantaged because of ethnicity, income, gender, class or sexuality (Strauss 1999). HIV vaccine trials often pose particular ethical problems, as participants generally represent communities where HIV infection rates are high and risky behavior is widespread. Given these dangers, participants need assurances that they will benefit from a vaccine if it proves effective or from access to care and treatment if they become infected during the course of a vaccine trial (Blanchard 1999; Strauss 1999).

This literature review will discuss a series of factors related to community involvement and participation in HIV/AIDS prevention research, including definitions of “community” and “participatory research,” the rationale for engaging communities, and the recent paradigm shift in HIV prevention research including changes in the role of researchers. A separate section will examine one model of community participation through community advisory boards (CABs), including a definition of CABs, different models, their purpose, obstacles that CABs face, and considerations for overcoming them. The review will also consider future prospects for community involvement in HIV/AIDS prevention research.

## Background

Historically, the aim of conducting medical and public health research has been to safeguard and improve the human condition, resulting in considerable benefits for individuals. Community participation in health-related research and practice is not a new phenomenon. During the 1970s, the emergence of neighborhood health centers in the United States made the issue of community involvement especially important. Early experiences proved that gaining the trust of communities was linked to the researchers' ability to address the priorities of community members (Merzel and D'Afflitti 2003). This point was clearly demonstrated by the example of a New York City family planning agency that hired eight low-income African-American and Hispanic women to conduct family planning-related community organization activities in their neighborhoods. The agency's health educator soon realized that the women had accepted their jobs because they needed the money and were actually distrustful of family planning efforts. The health educator put aside the agency's family planning mission and engaged the women in discussions about the pressing issues of their communities. The women identified irregular garbage collection and drug dealing as two of the most important problems. The educator advised the women on how they might deal with these and other problems and which agencies might be able to help. The women began to address the problems they had identified. Encouraged by their success and the family planning agency's interest in their welfare, several of the women took an interest in the issue of family planning, asked questions, and engaged in discussions with the health educator. "Following these discussions, six of the eight women became convinced that family planning was in the best interest of their communities and began doing effective outreach and organizing in their neighborhoods" (Minkler and Pies 1997).

In the early 1980s, researchers sought community involvement in the form of a program advisory committee, to guide prevention research focused on gay men in the large urban centers of the United States. The research, in tandem with community involvement, resulted in a 65 percent drop in the number of men who engaged in unprotected intercourse in target communities and a 50 percent increase in condom use. Using a similar approach among women in inner-city, low-income housing developments in five U.S. cities, researchers observed a 25 percent drop in the number of women in the intervention communities who reported engaging in unprotected intercourse over the previous two-month period and a 56 percent increase in the frequency of condom use among the same population, according to baseline and 12-month follow-up interviews (Fernández et al. 2003).

The emergence of community involvement and participation in research activities has been most notable in developing countries among populations who were suspicious of the motives of Western researchers, or in communities of U.S. minority groups, who began to resent serving as "subjects" for researchers who often exploited their circumstances for very little benefit to the community (Green and Mercer 2001).

In Uganda and Thailand, community mobilization and participation in HIV/AIDS research has been cited as changing the course of local epidemics and providing the world with some of the first success stories for HIV/AIDS prevention and control efforts (Hsu 1999; Lau and Muula 2004). However, the challenges of defining the various levels of community participation in research (Seely, Kengeya-Kayondo, and Mulder 1992), and of documenting and disseminating "best practices" of community involvement for adaptation in other countries and cultural contexts, remain daunting (Hsu 1999).

## Overview of Community Participation in HIV/AIDS Prevention Research

### “Community”

An exploration of the topic of community participation in HIV/AIDS prevention research calls for a definition of the concept of community as the first step. Yet this task is not simple. Researchers in the field of public health do not hold a common view on what “community” is or how it operates in the context of research. One possible definition is “a group of individuals with a common interest and who identify themselves as a group” (Labonte 1997). Some researchers maintain that modern communities are not necessarily defined by geographic proximity, but rather by “shared interests or characteristics such as culture, ethnicity, occupation, or a sense of purpose or vision” (Centers for Disease Control [CDC] 1998). Researchers involved in Project LinCs (Linking Communities and Scientists), which endeavored to create community support, trust and involvement in HIV vaccine trials in three U.S. research locations, developed the project based on a definition of community as “shared interests, common fate, social and political history, and cultural affinity” (Blanchard 1999). One of the three research locations had a large African-American population, yet people involved in the project maintained that many different African-American communities existed in the location (Strauss 1999). Based on interviews with members of the study population, the researchers’ ultimate definition of community was “a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings” (MacQueen et al. 2001). Another team of researchers, working on the issue of HIV/AIDS and community conflict in rural Nigeria, considered community to be “physical, geographical entities identified by their inhabitants as constituting a distinct location, such as villages, districts in towns, slum areas” (Gruber and Caffrey 2005). Finally, the CDC states that “[f]rom a participatory research perspective, ‘community’ should ultimately be defined in terms of those whose participation is necessary for the implementation of the research and whose well-being is likely to be affected by the conduct of the research” (CDC 1998).

### “Participatory Research”

The concept of participatory research also merits examination. At its most basic level, participatory research can be considered “research that is generated collaboratively in a partnership between scientists and others” (Green and Mercer 2001). Participatory research is the involvement in research design of all those who might use or benefit from the research, in coordination with other stakeholders, including public health practitioners, local government agencies, non-governmental organizations and others (*ibid*). Community participatory research is an approach rather than a methodology. Within this approach, researchers “bring skills in research design and methods and knowledge of health,” while community members “bring knowledge about the community’s culture, social norms, and networks” (CDC 1998). The two groups work together to define priorities and establish research questions that will be mutually useful and valid (*ibid*).

Participatory research may also be referred to as “community participatory action research” or “community-centered research.” This approach is a participatory and cooperative process that involves co-learning. It requires developing systems, building local capacity, and empowering participants. It also aims to create a balance between research and action: “[b]oth HIV/AIDS researchers and community-based organizations are partners and responsible for the conceptualization, needs analysis, development, implementation and evaluation of the program. As a result of this

process, community participants are empowered with the realization of their own capabilities to be researchers and to induce desired changes within their communities” (Morisky et al. 2004).

Community-based participatory research is not a research method. It simply serves as an approach to building community partnership and action for social and behavior change that contributes to HIV prevention and control (Morin et al. 2003).

## Rationale

Why is community participation in HIV/AIDS prevention research a topic of importance? One of the most fundamental answers to this question is that the people who form a community are the most direct link to making a difference within that community; public health research that aims to be successful cannot afford to overlook this resource when planning strategies (Merzel and D’Afflitti 2003). Collaboration between researchers and communities helps to ensure that communities invest themselves in the research, making data and results more significant for the community and “increas[ing] the likelihood for a successful project with mutual benefits” (Leung et al. 2004). Involving communities helps to ensure that research examines the variable and inter-related nature of research factors (*ibid*). Community participation also helps researchers achieve “better penetration of communities with more acceptable and culturally relevant messages, and greater sustainability of the intervention activities and effects” (Beeker et al. 1998).

Community participation in HIV/AIDS research can be instrumental in raising awareness about influences on HIV transmission within the community, producing attitude changes in community leaders and strengthening leadership capacity in the parts of the community most affected by HIV/AIDS. Community involvement can also help increase condom use, provoke a change in behavior among high-risk groups, decrease the incidence of other sexually transmitted infections, mobilize more community resources for HIV prevention, and empower community members to effect desirable change (Beeker et al. 1998; Morisky et al. 2004; Ramirez-Valles and Brown 2003). In the case of HIV vaccine trials, involving communities in research can help people and their communities “comprehend the complexities of HIV/AIDS vaccine interventions and to make informed decisions on their involvement” (Medical Research Council of South Africa 2000). A study about willingness to participate in an HIV/AIDS vaccine trial demonstrated that education about vaccine trials may positively influence the willingness of Ugandan military men to participate. (McGrath et al. 2001).

Another reason community participation is so critical to HIV prevention research is its contribution to establishing trust between the researchers and the researched. Project LinCs focused on the willingness of volunteers to participate in Phase III preventive HIV vaccine trials at three U.S. sites. This project used community participation “as a step toward improving the relationship between AIDS scientists and communities” and “sought to provide scientists involved in preventive HIV vaccine trials with a better cultural understanding of the needs and concerns of the communities from which they might recruit study participants” (Strauss et al. 2001a). In Cambodia, a two-year project on HIV prevention among migrant sex workers from Vietnam engaged community members in research; the goal of this effort was to empower participants to design and implement their own interventions by developing team-working skills and gaining the awareness that they were capable of making positive changes in their environment (Busza and Schunter 2001).

Moral and ethical considerations underscore the urgency of ensuring community participation in HIV prevention research. These considerations have traditionally focused on protecting the rights of trial participants. With increasing attention to this area in recent years, community input throughout the research process is becoming more imperative. “Without a strong commitment to real community participation, we risk undermining our future efforts and dissipating the often fragile trust that communities invest in us...Recognition of the importance of self-determination for communities, coupled with commitment to the concept of true partnership, must serve as guiding principles for ensuring meaningful community participation” (Minkler and Pies 1997).

## **Changing Paradigms**

In recent years, research scientists have gained increasing awareness of the benefits of involving communities in research. From an epidemiological standpoint, the argument is that focusing exclusively on individual risk ignores the social context of health and disease. Epidemiologists are encouraged to improve public health by focusing on underlying causes of disease; analyzing social contexts and systems; and incorporating the humanities, ethics, human ecology, and political economy into the concept of epidemiology. This shift away from the individual implies collaborating with the community in collecting and analyzing data, and helping effect structural change to promote health and prevent disease at the population level (Leung et al. 2004).

In the realm of HIV prevention, practitioners refer to a paradigm “drift” rather than a shift, citing the mounting interest in social and economic contributors to HIV transmission, attempts to increase community involvement in HIV/AIDS research, and efforts to build the capacity of communities to design sustainable HIV prevention programs (Beeker et al. 1998). This paradigm drift has led many programs to embrace participatory methods — such as peer education and tailored interventions developed in collaboration with communities at risk — in HIV prevention (Campbell and Mzaidume 2001) and in recruitment for HIV vaccine clinical trials (Newman et al. 2004). Community participation, combined with political and scientific leadership, is now often cited as the model of collaboration needed to develop an AIDS vaccine (Excler 2005). MacQueen and Cates (2005) recommend a framework that links prevention needs to the implementation of research results. This framework incorporates advocacy and policy, prevention research, acceptability research, operations and program development, and community participation into a coordinated and integrated reproductive health and HIV prevention research enterprise.

## **The Changing Role of Researchers**

The growing awareness of the importance of community participation in HIV/AIDS research and a shift away from traditional paradigms of public health have led to a changing notion of the role of researchers. Encouraging community participation requires the role of researchers to “shift from that of an expert who enters a community to deliver an intervention toward that of an advocate, collaborator, or mentor who assists community members in developing the resources, skills, and social networks to implement and maintain these programs” (Beeker et al. 1998). Researchers who value community involvement have to find ways to use the data generated by a research project to benefit community members. They must also maintain awareness of HIV prevention issues linked to ethnicity and gender (Strauss 1999). Researchers should focus their efforts on questions and methods that enhance community resources and capacity, and avoid exacerbating obstacles. To maximize community involvement, researchers should begin by asking questions rather than

offering solutions. They should help communities measure the differences their members make in the context of a research project, and share control over financial resources and decisions with the appropriate community members. And researchers should demonstrate their interest in building a trusting, equitable relationship with the community (Katz 2004). All of these activities will increase, not diminish, the responsibility of researchers to focus on and accommodate community concerns (Dickert and Sugarman 2005).

## **Establishing Community Participation**

Given all of the reasons why community participation in HIV/AIDS prevention research is essential, and recent changes in paradigms and research approaches, how can researchers and their colleagues mobilize community involvement? First, researchers need to learn about the communities with which they hope to work. They may need to conduct preliminary research on where communities are located, what their behavioral risk for HIV infection may be, and how community members feel about the issues of research and HIV/AIDS (Blanchard 1999). Second, it is important to ask for collaboration before a project is underway, rather than after design and planning are complete (Strauss 1999). This may involve going into the community and asking general questions about who is influential in the community and whose opinions and leadership are respected. Researchers may then want to conduct focus interviews with those whose names are suggested most often, and ask these individuals for further recommendations (Fernández et al. 2003). Researchers need to engage in in-depth discussions with a variety of possible stakeholders, including community leaders, representatives from community-based organizations, local government officials, health care workers, and others, depending on the focus of the project. Discussions should determine what expectations, priorities and benefits may be and what role community members would like to play (Gruber and Caffrey 2005). In the case of HIV vaccine trials and other preventive measures, all those involved in discussions should understand the significance of informed consent for participation in research. In some cases, researchers may need to provide specialized training to community members to ensure their full participation in future research. Some activities that have expanded community participation in HIV prevention research (Lo and Bayer 2003) include placing community representatives on institutional review boards, advocating for principles of respect for community, establishing guidelines for community consultation and consent (Dickert and Sugarman 2005), involving community representatives in pilot activities, partnering to determine research priorities and design (Woodsong and Karim 2005), and establishing community advisory boards (CABs). Because of their unique history and role in HIV/AIDS prevention research activities (Cox et al. 1998), CABs will be covered in more detail below.

### **One Model of Community Participation — Community Advisory Boards**

In 1989, the National Institute of Allergy and Infectious Disease's (NIAID) Division of AIDS funded 17 research units to conduct research on treatment for HIV. These units were known as the Community Programs for Clinical Research on AIDS (CPCRA) and were developed in response to a growing AIDS activist community that was sometimes adversarial. The CPCRA was the first National Institutes of Health-funded initiative that required a CAB to help design and implement research studies. The purpose of the CAB at that time was to “strengthen community representation within clinical trials research programs by having people infected with and affected by HIV disease participate in meetings, planning and decision making” (Cox et al. 1998).

One of the most important roles of CABs is to serve as a bridge between researchers and prevention trial participants. Successful CABs are “actively connected to diverse people in their local communities and empowered to function in ways that are meaningful to their community base” (MacQueen et al. 2001). Community advisory boards may be involved in a project during its test phase, helping to create, review and adjust the design of a project (Woodsong and Karim 2005). They also may contribute to improving the quality of research protocols by offering feedback and constructive criticism. They may explain possible advantages and drawbacks of participation in research to community members, and they may also help identify and resolve ethical issues related to a research project (Morin et al. 2003). In the same vein, CABs can be instrumental in safeguarding the rights of research participants, by, for example, ensuring that potential participants fully understand the issue of informed consent and their right to refuse. Community advisory boards can also help develop materials that explain a research project to potential participants and establish recommendations to help them decide whether or not to participate (Strauss et al. 2001b).

Community advisory boards generally consist of community members who represent stakeholders in a research project and who have a similar identity, history, culture and mode of expression. A CAB may focus on a specific HIV/AIDS research population, such as sex workers, young people, injecting drug users, men who have sex with men, or a particular ethnic group. Community advisory board members often include representatives of nongovernmental and community-based organizations, and sometimes local government officials, members of patient advocacy groups, health care workers, and others. In general, CAB members should be people who can effectively express community needs and concerns to researchers and communicate with other community members about HIV/AIDS prevention trials (Morin et al. 2003; Lo and Bayer 2003).

### **Models of Community Advisory Boards**

Researchers have described two different models for CABs. The “broad community model” is characterized by “representation from a cross section of the larger community, including government officials, religious leaders, nongovernmental organization officials, and people living with HIV infection” (Morin et al. 2003). The “population-specific model” consists of representatives from a group whose situation or behavior puts them at risk for HIV infection. These populations might include women, injecting drug users, or men who have sex with men (*ibid*).

### **Community Advisory Board Challenges**

Not all researchers have been receptive to the notion of CABs participating in the research process. Resources devoted to CABs are often limited and may be eliminated from budgets in the interest of protecting other research priorities (Strauss et al. 2001b).

Some researchers may consider CABs to be a token gesture made to pacify communities or to satisfy funding requirements. In these cases, CAB members may feel that their role is primarily decorative, and that researchers who seek feedback from the board will ignore their input (Strauss et al. 2001b; Minkler and Pies 1997). During a study designed to evaluate the safety and effectiveness of the drug tenofovir to prevent HIV infection among injecting drug users in Bangkok, Thailand, several groups of community activists came together to protest the trial. In a letter addressed to researchers involved in the project, they wrote that “[t]he community, particularly the Thai Drug Users’ Network (TDN), should be treated as equal partners in the planning of a more ethical trial with genuine community involvement... We insist on true involvement in the

process of planning, implementing, monitoring and analyzing/disseminating results of the trial, and will not accept a token role on a Community Advisory Board (CAB) that is established after the protocol, which we find deeply flawed, is essentially fixed” (AIDS Info NYC 2004).

Even when a CAB is established in good faith, questions may arise about what role it should play and how its power and functions differ from those of academic researchers. For example, should CAB members be considered co-investigators? Should they decide where and how to spend research funds? Should CAB members receive compensation, and if so, how much (Strauss 1999). Compensation for CAB members can provoke jealousy and animosity among other community members, as can the sense that CAB members are singled out for special treatment in the community. The fear also exists that CAB members may use the skills they acquire through training and access to other levels of society to manipulate members of the community (Minkler and Pies 1997). Finally, CAB members may be the target of discrimination by community members who correctly or incorrectly associate them with HIV infection (Blanchard 1999).

## **Successful Community Participation**

The measures of the success of community participation in HIV prevention research include both the results of a project and the degree to which a community benefits from its involvement. Successful community participation in HIV/AIDS prevention research is linked to establishing relationships with a variety of community members; welcoming different cultural perspectives; lending equal value to community and academic views; and agreeing on the need for flexible research methods (Katz 2004). Genuine community involvement means that communities participate in research not just at the design or evaluation stage, but throughout the entire process. In the context of HIV vaccine trials and other types of prevention research, communities are essential to ensuring the accuracy and effectiveness of informed consent. They should both help design the informed consent process and evaluate whether vaccine trial and prevention research participants are giving truly informed consent to researchers (AIDS Vaccine Advocacy Coalition 2005; Dickert and Sugarman 2005).

Research projects that successfully involve community participation often contribute to change among individuals, groups and organizations, as well as policy and environmental changes. Community-based HIV/AIDS prevention research may produce changes in sexual behavior and drug use in populations at risk and may also help change community norms and make risk avoidance more acceptable (Merzel and D’Afflitti 2003). HIV/AIDS prevention research with legitimate community involvement inspires participants to develop systems that are useful for their community, to build local capacity and to gain control over their lives. In most cases, true participation takes time and requires continual renegotiation and discussion (Gruber and Caffrey 2005; Leung et al. 2004). Successful researcher and community partnerships include enhancing protections for communities, enhancing benefits to participants, conferring legitimacy to interested parties and stakeholders, and sharing responsibility in the outcomes of the study (Dickert and Sugarman 2005).

## **Obstacles**

While this review has offered much evidence on the desirability of community involvement in HIV/AIDS prevention research, factors exist that can impede or hinder the participation of communities. In some cases members of a community may distrust researchers because of past

experience or rumors about the drawbacks of participating in research (Fernández et al. 2003). Participants in vaccine trials also face the risk of future misdiagnosis due to antibodies produced by immunogenic vaccines. They may also face discrimination based on their association with HIV infection or with groups considered to be at risk for acquiring the virus (Blanchard 1999). The time factor in involving communities in research and the resulting delay in publishing results may make academics hesitant to engage in participatory research (Katz 2004). Even when academic researchers are committed to community involvement, they may have to confront conflicting loyalties to employers, communities and funding sources (Minkler and Pies 1997).

In addition to differing goals and priorities between academic researchers and communities, communities themselves may not agree on the focus and purpose of HIV/AIDS research, with different groups of stakeholders favoring different priorities (Merzel and D’Afflitti 2003). Differences such as social organization, hierarchies, gender inequities, sexuality and relative poverty may divide a community. In an HIV prevention project that took place in rural Nigeria, disagreements between young and older members of the community undermined activities, with the result that “[n]either the community gatekeepers nor the wider community had an opportunity to participate in the prioritization of needs and definition or development of interventions, or to monitor and evaluate activities” (Gruber and Caffrey 2005). Rumors of financial gain and impropriety by community participants also destabilized the project (*ibid*). Researchers working with Vietnamese sex workers in Cambodia also encountered the complication of resistance to the project from brothel owners, who exerted control over the sex workers and failed to see how the project would serve their interests (Busza and Schunter 2001).

Although community participation in HIV/AIDS prevention research may generate a wide array of potential benefits, some situations may make equitable community involvement difficult to the point of being nearly impossible. In the case of the HIV prevention project in rural Nigeria, community rifts proved daunting to researchers and fatal to the implementation of HIV/AIDS activities. More in-depth discussions and possibly a great deal more time with the community would have been necessary to establish the desired level of community participation (Gruber and Caffrey 2005). If a project lacks time and resources, its impact on the health of a community may be limited and weak (Merzel and D’Afflitti 2003). Finally, the urgency of responding to the HIV epidemic in a timely manner may sometimes call into question the use of protracted dialogue with all levels and groups of a community if there is a possibility that a quick response — at least in the initial phase — may save lives (Fernández et al. 2003).

## Issues for Future Consideration

Several factors may affect the trajectory of community involvement in HIV/AIDS prevention research in the future. Researchers whose programs include community participation should consider how much and what kind of effect the programs are likely to have on the community in question. Even a small reduction in the risk of HIV transmission can have important implications for the health of a community. HIV/AIDS research programs should also consider what the realistic outcomes of their research will be, and to what degree they will or will not be able to reduce the incidence of illness and death. Researchers should take into account the inadequacy of traditional evaluation methods in exposing the subtle and complex nature of community change. Research programs should ensure that they target not just individual risk factors but factors that

affect the entire community. Health promotion theories must also take into account the social context of behavior rather than just individual changes. Many programs should focus on all levels of a community, rather than just high-risk groups, with messages capable of reaching the entire community. A three-tiered approach may be most effective in inducing change: one strategy for individuals, another for the community, and a third that targets policy change. Researchers should also respect the ability of a particular community to incorporate change, including the community's resources, skills, networks, leadership, values and history (Merzel and D'Afflitti 2003).

## Conclusion

Community involvement and community participation in health-related research are not new concepts. They have, however, attained renewed significance and effectiveness in the response to HIV/AIDS. The mounting statistics in the face of new HIV infections, the cost and sometimes unavailability of adequate treatment, and the still unfulfilled promise of a vaccine have made it essential to work with and through communities in researching approaches to preventing the spread of the virus. Challenges remain, but considerable evidence supports continuing our efforts to engage communities in the research agenda. This review has endeavored to shed light on how community involvement in HIV/AIDS prevention research takes place and the specific ways in which it can contribute to the collective response to the pandemic.

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