

“Are Researchers The Hardest To Reach Population?”

Communities, Collaboration, and Politics

In HIV Prevention Research

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Introduction

A discourse exists asserting that researchers and community members have increasingly entered into partnerships of collaboration on projects concerning HIV prevention. However, the very nature of these partnerships has often been taken for granted, or defined via the perspective of researchers. While community member participation in HIV prevention research projects has become a common occurrence, there has been very little work done evaluating the nature of such partnerships (Morfit et al., 2006). As a result, it is unclear if community members actually participate in generating research projects and agendas, or if community members participate by way of providing token input. In addition, questions remain regarding the access that community members have to researched materials. The purpose of this report is to illuminate these issues by focusing on two broad areas concerning both researchers and communities who are interested in issues concerning HIV prevention. The first of these areas is how community informs research concerning HIV prevention. More specifically, we seek to shed light upon the ways that community members generate new ideas and set the agenda for research. The second area focuses on issues regarding the dissemination of research, in particular, how research and data should best be shared with community members.² While this report certainly will not answer all of these questions in detail, we hope that the findings and recommendations provided will help both researchers and community members enhance their collaborative process.³

Brief History and Literature Review

Most of the primary literature on the collaborative process between researchers and community members has focused on the function of Community Advisory Boards (CABs). Historically, CABs related to HIV/AIDS research initially formed in the late 1980's in order to involve people living with HIV/AIDS in the medication trial/research process. Until the late 1980's, the meetings of AIDS research groups did not include patient representatives but this changed after activist campaigns. Thus, CABs

² Concerning dissemination, the focus of this report is on the dissemination of HIV prevention research and not focused on information for the purpose of behavioral change, such as social marketing campaigns.

³ This study was conducted in San Francisco, California. However, the researcher also sought information from geographical sources beyond the San Francisco area.

developed out of the need for community based clinical trial research, not prevention (Cox et al., 1998). The first CAB was developed by the Community Consortium at San Francisco General Hospital in 1988, and 17 community based AIDS research units developed CABs based on this model. Currently, CAB membership makeup varies by agency and location, but most say that their members include service providers, community activists, various professionals, and trial participants. Membership can vary from between five members to over 20 members, but CAB membership appears to constantly change as people leave due to new obligations, moving, burnout, and death. Today, government funded clinical trial networks are required to establish CABs. This makes the “community” aspect of CABs problematic, as it often becomes unclear if the CABs commitment is to a community or if a CAB is simply meeting governmental requirements. While CABs began in the United States, they have spread to different parts of the world as a result of the international effort to provide services to people living with HIV. For example, in 1999 the first African vaccine trial was established in Uganda. However, once again, these international CABs are mainly concerned with clinical trials.

Literature concerning collaboration between researchers and community members where community is involved in setting the HIV/AIDS research agenda is much more sparse.⁴ The literature that does exist on how communities inform HIV research usually falls into one of the following categories: the prevention needs of men who have sex with men (MSM) (Crosby & DeCarlo, 2000), how service providers and researchers collaborate (Goldstein, Freedman, & Wohlfeiler, 2001), and community consultation (not participation) in the research process (Morin et al., 2003). Morfit et al. (2006) has focused directly on community involvement in HIV prevention research, specifically community participation in the HIV Prevention Trials Network (HPTN). However, their report mainly deals with a CAB, and focuses on how collaboration should be assessed rather than the nature of collaboration. What is clear is that very little literature exists on how community members actively set the agenda for HIV prevention research projects, or how such research is being disseminated back into communities. Further work in these areas is absolutely necessary.

⁴ This research methodology is also known as community based participatory research.

Methodology

Inherently interpretive, this report was grounded in qualitative methods, which was appropriate for gathering information concerning the insights of researchers and various community members. A total of 13 interviews were conducted over a period of three months.⁵ Interviewees were selected based on their association with one of five domains: the San Francisco Department of Health, research/academia, community members, media, and CAB members. An interview question bank was then generated for each of the domains, and the researcher contacted relevant individuals for an interview. Individuals in the community domain were chosen during community outreach sessions with the STOP AIDS Project. Researchers proved to be the most difficult group of individuals to contact, moving us to ask, “Are Researchers The Hardest To Reach Population?” Pseudonyms have been used in this report to protect interviewee anonymity.

In addition to these interviews, field notes were collected at several community forums and CAB meetings. A survey about where individuals receive their health information was also conducted at a community forum. Following the collection of data, the researcher coded the material to analyze recurring findings and recommendations. The scope of the project was limited by two factors, the brief time constraints of the study as well as the small sample size. However, the intention of this report is not to give an all-encompassing overview of the topic but to describe the findings and recommendations that were generated over the three-month period.

Key Findings

1. Very little dialogue exists between HIV researchers and community members concerning HIV prevention research.

“Do venues exist for researchers and community to come together?”

“Gut knee jerk response, no! As expected, for me being an educated female who has exposure and access, yes if I look hard enough. Very, very hard!”

Elizabeth Smith (Community Member)

⁵ Interviews were conducted during August, September, and October of 2008.

When asked if they believed that venues existed for community members and researchers to come together and collaborate, almost every interviewee said no. Further, each interviewee interpreted the word “venue” to mean a community forum. This alludes to the idea that there is an understanding that collaboration must happen in the space of a community forum rather than through, for example, focus groups or online.

Only one researcher stated that venues do exist, but claimed that the only venue he could recall was created through the HPPC (HIV Prevention Planning Council). While the HPPC works to guide HIV prevention efforts in San Francisco, these public meetings have little influence upon the agenda of researchers. However, it must be acknowledged that interviewees agreed that it is difficult to bring community members together under the heading of prevention. Questions loom over who has the time to invest and who does not, and there is a sense that community members will not directly participate in such efforts unless they are impacted directly, or an incentive is offered. Some suggest that a more effective way for community members and researchers to collaborate is via the Internet. While we do see little effort being made to bring together researchers and communities through forums, it is clear that CABs are making an effort to bring engaged community members into the research process. For example, the Center for AIDS Prevention Studies (CAPS) CAB holds meetings in which members are asked about issues of community-based research. Questions asked at one of these meetings included: 1) Is the Technology and Information Exchange (TIE) Core focusing on the right things? 2) How can the TIE-CORE ensure that it is being open and communicative about research? 3) How is the TIE-CORE perceived in the community and how can we better this?

2. Most community members feel like they are not part of the HIV prevention research process.

Those who are part of the process feel as if they are the objects, not agents, of research.

“Have you had any interaction with HIV prevention researchers?”

“No.”

“Would you like to be an informant in that type of research?”

“Yes.”

Chris Harton (Community Member)

There is a general consensus that community members feel as if they are the objects to be researched, and not active agents in research projects. As community activist Allan Green stated, “Very few researchers talk to communities before they, for instance, write grant proposals. They need to do this if they are taking community seriously.” Part of this is associated with the nature of academia, as individuals are often intimidated by the “expert” status of researchers. Another issue is that many participants in projects focusing on HIV prevention in San Francisco have contacted community members with the hopes that they will participate in an already established project, not to help craft a project. Researchers agree that those involved in HIV prevention research need to be trained in community based participatory research. Nevertheless, the San Francisco based HIV Prevention Trials Network (HPTN) Collaborative Council⁶ provides a good example of how community members can participate in the formation of a research project. Community members involved in the HPTN are actively participating in the creation of a research agenda and in deciding the means by which data will be collected. But those involved in the HPTN are considered to be service providers of the community, and many are already involved in HIV prevention efforts.

Questions need to be asked of what we mean by community when we push for community involvement. Interviewees had very different ideas on what community means. While researchers stated that they do receive community input through CABs, many members of these CABs are already involved in HIV prevention services and activism. Should we consider these individuals as members of the community? Questions also need to be asked of how a one-sided focus on including the community can hamper HIV prevention research efforts. Researchers see community based participatory research as a good thing, but how can this method problematize the research process? What is clear is that very few research projects are involving community members at the state of inception, and research institutions should push for the creation of more research projects that are grounded in collaboration with community members.

⁶ The HPTN is a group of research studies. We interviewed a person working on one of the studies.

3. There is an extreme sense of suspicion of researchers in communities of color.

“How would you describe the community’s perception of researchers?”

“Fear, and that researchers don’t have community member’s best interests in mind...The researchers that I’ve come into contact with did not look like me, and did not talk like I talk, even though I can navigate a lot of different communities.”

*Nichole Richards (HIV Counseling/Testing Linkage
Coordinator)*

When asked about what the general community’s perception of researchers might be, most interviewees said that the general population has a positive outlook on researchers. However, it is clear the general population can be interpreted as being white, and those interviewees who were of color stressed the fact that their communities do not trust researchers. One interviewee asserted that Latinos believe that researchers fail to care about their family and health care needs, while African-Americans have a deep distrust of research resulting from historical atrocities and living in a racist society. Another interviewee suggested that some current distrust results from the work of University of California San Francisco researchers, who have gone into low-income communities of color, as well as immigrant communities, and offered grocery vouchers in exchange for people participating in a vaccine study. There is also a notion that the very racial identity of the researcher may have an impact on how the researcher is perceived. Several interviewees stated that they would like to interact more with researchers of color.

4. Most agree that researchers could better collaborate with community members by disseminating findings back into the community via written work, personal interactions, media, and/or community meetings conducted in a timely manner.

“If you were to interview HIV prevention researchers they have no plan and no history of disseminating information back into the community, only to academics. By the time they have published their findings the community has moved on. Information needs to be circulated back into the community.”

Allan Green (Community Activist)

Interviewees agree that community members feel used and abused when researchers utilized what has been called the “helicopter method” of conducting research. In this method, researchers drop into a community, collect data, and then leave. No information concerning data and findings is later disseminated to the community. There is consensus that a realistic connection must be formed with communities about results. Although some researchers are creating publications that are “community friendly,” we should not assume that all such documents are finding their way back into communities. For instance, researchers at CAPS have developed a wonderful set of fact sheets that are accessible to a public audience and posted them online for public usage. However, when asked where they received their health information, no community member mentioned the CAPS fact sheets. We also must ask questions regarding effective dissemination of researched materials when dealing with low-income communities. For example, dissemination via the Internet may not be a viable option if many people living in the community involved in research do not own, and cannot afford, computers. A concerted effort should be built into the research design to recycle data and findings back into communities in a timely manner, and factors in the ways that community members receive information.

5. Concerning dissemination, interviewees mentioned several campaigns and a cluster of key websites that they thought were beneficial.

Interviewees mentioned several social marketing campaigns that they thought were very successful: HIV Stops With Me and the Healthy Penis campaign (addressing syphilis). When asked where they receive information concerning sexual health, most community respondents mentioned three websites:

- The Body.com
- San Francisco City Clinic
- WebMD

Recommendations

Input

1. Researchers, community based organizations, etc. may want to work with websites and/or search engines to figure out what are the most commonly asked questions regarding HIV. Researchers could respond by conducting further studies on the issue. This could be an example of a community asking a question to which researchers directly respond.
2. Regular discussion groups should be established with researchers and community members where researched documents can be discussed and relationships for future collaborative research can be created.
3. Researchers may want to consider doing qualitative studies prior to developing a research protocol. Going into communities and doing one-on-one interviews and focus groups before a proposal is established could prove to be very useful.

Dissemination

4. Researchers should ensure that data and findings are circulated back into the community. This can happen via personal interaction, community forums, or producing a publication that is immediately made available to the community. One way that data can become immediately accessible is through posting on popular online sites (thebody.com), or in media publications (Bay Area Reporter or the San Francisco Chronicle).
5. Researchers should be trained in the art of interacting with the media so that they can interface more effectively and provide key messages that can reach communities.

Research Collaboration

6. It is necessary to establish community forums that focus on reporting the findings of research in a manner accessible to the public. This can either be done in person or through new Internet technologies such as chat rooms, message boards, or web blogs.
7. Researchers should be trained to do community based research (i.e. community based participatory research). As a result, better relationships may be built with communities.

8. Concerning the issue of race and research, a long-term focus could involve urging more people of color to pursue careers in research. Short term focuses could include; 1) conducting cultural competence training with researchers, and 2) hiring people that represent the communities that are being researched.
9. Community members who are interested in becoming part of the research process should go through some type of training so that they can know what their role can be in the research process, and so they can develop the ability to effectively read and comment on research documents.

Conclusion

The findings and recommendations highlighted in this report are not intended to provide closed solutions to issues concerning collaboration between communities and researchers, or dissemination. Instead, the hope is that they can initiate a conversation between researchers interested in working with communities and community members so research on HIV prevention can be conducted in a way that is relevant for all. The very social nature of HIV forces us to rethink the very boundaries that have been constructed between academia and the general population. Thus, HIV prevention research moves us not only to reconsider research practice and who constitutes a researcher, but also how we can create research projects that have an actual impact on saving peoples lives.

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