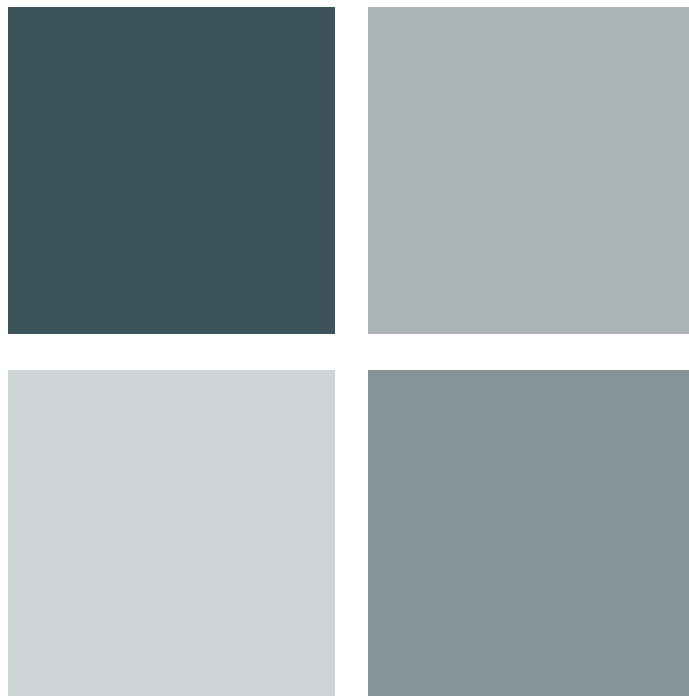


## Lessons Learned from Boston, Massachusetts, USA





# Fenway Community Health Center

<b>Article Authors</b>	<b>Darren LeBlanc, BS, community education/outreach coordinator Jim Maynard, MDiv, community outreach, recruitment, and education program manager Members of the Fenway CAB</b>
<b>Study Populations</b>	<b>Men who have sex with men, serodiscordant couples</b>
<b>Key Topics</b>	<b>Recruiting people of color as study participants and CAB members, community outreach activities, confronting apathy toward HIV/AIDS</b>

## Introduction

AIDS, initially called “gay-related immune deficiency,” was first recognized in the United States in the early 1980s. While HIV has long since spread outside the population that it originally affected in the United States — men who have sex with men — it remains a problem within that population. Although AIDS mortality declined 45 percent from 1996 to 1997, when effective antiretroviral treatment became available, HIV/AIDS has become particularly problematic among African-Americans, for whom it is the leading cause of death of those aged 25 to 44, and among Latinos, for whom it is the third leading cause of death of those aged 25 to 44. Approximately 22,000 to 24,000 Massachusetts residents are currently infected with HIV; 27 percent of these cases occur in African-Americans, and 24 percent are Hispanic. At the same time, African-Americans and Hispanics represent only six percent of the general population, and are thus disproportionately affected by HIV/AIDS. The HIV prevalence rate among all people aged 15 to 49 in the United States is currently 0.6 percent (GMHC, UNAIDS).

In 2000, the United States National Institutes of Health selected Fenway Community Health in Boston, Massachusetts, to be part of the HIV Prevention Trials Network (HPTN), coordinating an HIV Prevention Trials Unit (HPTU) that included Fenway, Miriam Hospital in Providence, Rhode Island, and YRGCare in Chennai, India. Community activists founded Fenway in 1971 as a grassroots neighborhood clinic. Today it serves nearly 12,000 patients per year (of whom more than 1,000 are living with HIV) and is one of seven community health centers in the United States specializing in the care of lesbian, gay, bisexual and transgender populations.

## HPTN Research Projects in Boston

The Fenway research department and its community advisory board (CAB) first collaborated on a research study entitled “Explore!” (HIVNET 015, a randomized clinical trial on the efficacy of a behavioral intervention to prevent acquisition of HIV among men who have sex with men). In Boston, Explore! compared an intensive individualized behavioral intervention with standard

counseling and testing as an HIV prevention strategy. The study's cohort consisted of 729 men, including 100 recruited by the Latino Health Institute.

In partnership with the Brigham and Women's Hospital in Boston, Fenway Community Health is preparing to collaborate on a second research study, HPTN 052, a randomized trial to evaluate the effectiveness of antiretroviral therapy plus HIV primary care versus HIV primary care alone to prevent the sexual transmission of HIV-1 in serodiscordant couples. The primary objective of the study is to compare the rates of HIV infection among partners of HIV-infected participants in the following two study arms: 1) Antiretroviral therapy upon enrollment plus HIV primary care; 2) HIV primary care, without initiation of antiretroviral therapy until the participant has two consecutive measurements of a CD4+ cell count < 200 cells/mm<sup>3</sup>, or develops an AIDS-defining illness. More information about the HPTN studies involving Fenway-Brigham and their CAB is presented in Table 6.

## Community Advisory Board

### Establishment

The research department of Fenway Community Health recruited its first CAB for Explore! through referrals and word of mouth from people associated with the Fenway clinic as well as from general contacts in lesbian, gay, bisexual and transgender communities. Fenway also made use of public and community sources such as research forums, outreach activities in local bars and clubs, the Fenway Web site, and other online resources, including the lesbian, gay, bisexual

Table 6. HPTN Research Studies in Boston			
Study #	Protocol and Purpose	Study Population in Boston	Other Sites
HIVNET 015	<p>Trial of the efficacy of a behavioral intervention to prevent HIV acquisition among men who have sex with men.</p> <p>The study took the form of a "screening" trial of 4350 men who have sex with men, who were HIV-antibody negative, and who reported engaging in anal sex within the 12 months prior to enrollment.</p>	729 sexually active, HIV-negative men who have sex with men.	Chicago, Denver, New York, San Francisco, and Seattle, USA
HPTN 052	<p>Phase III trial to determine the effectiveness of two treatment strategies in preventing the sexual transmission of HIV in HIV-serodiscordant couples.</p> <p>Purpose: to determine whether antiretroviral therapy can prevent the sexual transmission of HIV-1 in HIV-1-serodiscordant couples.</p>	1,750 HIV-serodiscordant couples in all study sites.	Blantyre and Lilongwe, Malawi; Chennai and Pune, India; Harare, Zimbabwe; Porto Alegre and Rio de Janeiro, Brazil; Chiang Mai, Thailand.

and transgender listserv of the Massachusetts Institute of Technology. The Fenway CAB draws strongly from the Boston area academic community, which encompasses dozens of colleges and universities. The CAB also networks with other agencies serving a similar clientele. The CAB's mission is to present community perspectives and provide informed commentary to researchers, outreach workers and community educators about the conduct of research studies, particularly concerning strategies to educate, identify, recruit and follow individuals participating in studies. The CAB also provides input on appropriate risk-reduction education, counseling methods and the establishment of referral networks for medical and support services. Community advisory board members help develop strategies to measure risk behavior, approaches for informing the community, and tactics for achieving community support for future biomedical and behavioral studies.

Fenway has also formed a joint CAB with the Brigham and Women's Hospital for the HIV Vaccine Trial Network and works closely with Brigham and Women's Hospital in the recruitment of participants for vaccine protocols.

## **Members**

The Fenway CAB currently consists of 15 members, including 12 men and three women in their 20s through 50s. Nine of these individuals consider themselves gay, and one has self-identified as HIV-positive. CAB members are Caucasian-American (10), Asian (1), Asian-American (1), Pacific Islander (1), African-American (1), and Latino (1). Community advisory board members include representatives of AIDS service organizations, the medical field, science, business, publishing, health administration, information technology, and academics (including one student). Despite a certain amount of diversity among CAB members, some feel that the CAB could be more representative of stakeholders, including African-Americans, Latinos, and for the purpose of future research studies, women.

## **Training**

Community advisory board members have attended training workshops at national HPTN and HIV Vaccine Trials Network full group and regional meetings, as well as monthly ongoing training on general topics such as informed consent, "HIV/AIDS 101," and community ethics. Members also participate in periodic retreats for strategic planning.

## **Community Advisory Board Activities**

The Fenway CAB meets regularly on the first Monday of each month. In addition to their regular meetings, CAB members attend special meetings and have helped host research forums sponsored by Fenway Community Health. Community advisory board members played a key role in sharing the results of Explore! both with the enrolled cohort and through a subsequent forum with the entire community. At each event, the CAB successfully recruited additional members. A typical Fenway CAB meeting includes the presentation of scientific updates; additional presentations by the study's principal investigator, Fenway researchers, and visitors; and a discussion of community news, network news, and news from partners, such as local AIDS service organizations and community-based organizations.

## Community Advisory Board's Roles in Research Methodology

While working on the Explore! study, CAB members reviewed protocols, informed consent forms, and educational and promotional materials. The CAB assisted the recruitment team by giving valuable feedback on all proposed advertisements, including the modes and venues most likely to reach the target audiences reflected in the board's cultural and ethnic makeup. Members helped address questions such as:

- Which newspapers provide the best access to the population?
- Does radio or cable promotion reach those needed?
- Will images and language used in print ads, posters, and bar cards connect with potential volunteers?

The CAB served as an informal focus group, thereby supplying a valuable resource to Fenway research staff.

Community advisory board members have also helped develop community education activities such as the Annual Fenway Research Forum, where a wide range of HIV-related protocols are presented and explained. In addition to recruiting new CAB members, the CAB has also taken an active part in training new members.

## Community Involvement Activities

Fenway Community Health has a rich history of community involvement activities. Fenway staff members carry out nearly 40 outreach events each year, including community and college presentations, information tables at health events, and major community events such as Boston Gay Pride and Boston College Fest for incoming students each fall. Fenway sponsors events such as National Latin American AIDS Awareness Day and World AIDS Day, often with the participation of CAB members. As a free walk-in clinic, Fenway has been a fixture in the Boston lesbian, gay, bisexual and transgender communities from its early days. Fenway also runs the largest safe sex outreach work program in the state with some 70 trained volunteers conducting weekly outreach in bars, clubs, and public sex areas.

In the framework of Explore!, CAB members and other study staff gained entrance into the community through outreach activities, advertising campaigns and printed materials, and inter-agency referrals. Recruitment venues included local gay bars and clubs, a sex club, and local gyms with a large clientele of men who have sex with men. Special events where recruitment took place included Gay Pride events and similar activities catering to men who have sex with men. Institutional review board-approved advertising focused on newspapers such as *Bay Windows and Innewsweekly*, but Explore! also developed posters (with tear-off tabs at the bottom featuring the Explore! telephone number), cards for distribution at clubs, and other supportive materials. The Fenway Community Health Center's anonymous testing site was instrumental in referring potential participants to the study. One-on-one Explore! outreach activities were responsible for recruiting the majority of study participants. Partnership with the Latino Health Institute was key to enrolling Latino men who have sex with men. The Latino Health Institute is the best known and most recognized agency working with this population in the Boston area.

Community leaders responded well to the outreach involved in Explore! recruitment. They were able to understand the difference that the Explore! behavior modification protocol could make for communities of men who have sex with men. Bar and club owners were key partners in providing access to their venues and the support needed to recruit several hundred men.

## **Challenges**

Fenway Community Health and its CAB have faced a number of challenges in implementing the Explore! study, particularly in terms of reaching the communities most affected by HIV/AIDS within the target population. It has been difficult for Fenway and its CAB to recruit both new CAB members and research participants from communities of color, including African-Americans and Latinos. This problem, which impedes both recruitment and education efforts, appears to affect many U.S. efforts to conduct research on HIV prevention.

### **Recruiting research participants from communities of color**

Recruitment of study volunteers from communities of color has been challenging. Although there has been some success in recruitment for screening, most of those individuals screen out for a variety of reasons or simply decide at screening not to enroll in the studies. In an effort to respond to this challenge, Fenway subcontracted with the Latino Health Institute to recruit men who have sex with men from the Hispanic community to participate in Explore! Results were encouraging. Latino Health Institute staff members recruited more than 100 Spanish-speaking men and provided them with study-specific counseling and follow-up services. Partnering with a trusted member of the community and providing all services in Spanish were key to this effort. A Latino Health Institute staff member is now part of the Fenway CAB, thereby providing a valuable interface for work in both agencies. Fenway has cosponsored events such as National Latino AIDS Awareness Day and an all-day forum on the use of the drug crystal meth, which is reaching epidemic proportions among men who have sex with men in the Boston area. Fenway also works with the Multicultural AIDS Coalition, a trusted member of the African-American community. One of the coalition's primary projects is the "Faith Initiative" program, which conducts outreach with African-American churches in the Boston metro area. Fenway helped present a research forum at one church, and continues to do so on a quarterly basis.

### **Recruiting CAB members from communities of color**

Fenway is fortunate to have a large and committed CAB. However, one continued challenge is achieving broader representation, including more women, college-age students, and people of color. However, as with most or all other HIV Prevention Trial Network sites in the United States, barriers of mistrust and confusion over the goals of HIV/AIDS research are inherent in the communities that stand to benefit most from research trials. Partnering with community-based organizations and AIDS service organizations such as the Latino Health Institute, and activities such as the Faith Initiative with African-American churches have helped Fenway and its CAB achieve some progress in diversifying the CAB. Additional success has occurred through targeted recruitment, such as asking individuals already known to CAB members to join the board, as opposed to simply listing the need for additional members on the Fenway Web site, which most often results in contacts from additional gay white males. Still, the Fenway CAB feels that much remains to be done in terms of achieving equitable representation of the communities most affected by HIV/AIDS in the Boston area.

## Confronting apathy toward HIV/AIDS

Apathy around HIV/AIDS research has been a formidable barrier to community mobilization and education. While the challenge is ongoing, events such as the Annual Research Forum or the Explore! Forum have proved helpful. These events have provided a means for communities to ask direct questions of researchers. Fenway also provides a Living Well program, a series of educational events (typically seven per year) that addresses topics of concern to gay and bisexual men. These forums provide ample opportunities to discuss research and the difference it can make in the lives of men who have sex with men. In addition to the Living Well program, the Boundless program has helped to engage the community in research activities. Boundless, is a series of four educational events per year geared toward women and their health concerns.

## Lessons Learned

Fenway Community Health and its CAB have learned a number of lessons about community involvement in HIV prevention research.

### ***Approach the community for involvement in HIV prevention trials***

Working with men who have sex with men in the Explore! study, Fenway and its CAB have found that men who actively embrace gay culture are more willing to speak with recruiters. Photographs of high-profile gay men are effective in raising interest in a study like Explore! Strong partnerships with local gay groups (including the managers of gay clubs and bars) are instrumental in reaching potential participants. Also, local periodicals that serve the gay community are effective vehicles for raising awareness. Speakers' bureaus, however, are difficult and demanding to organize, and may not be effective enough to warrant the necessary investment of time.

Through Explore!, Fenway and its CAB also found that participant recruitment that uses speedy follow-up and persistent calling has a high rate of return. Yet, as noted in the previous section, reaching out to men in communities of color and recruiting them for studies can be difficult. Partnering with community-based organizations that work primarily in these communities, such as the Latino Health Institute, has helped Fenway achieve some success in this area.

### ***The community must contribute to research methodology and design***

Networks involved in research methodology and design currently reflect the interests of scientists and researchers. But Fenway and its CAB believe that these networks must also represent the interests of communities, because without this perspective research efforts are less likely to be successful. Community advisory boards must have a role in both protocol development and review of informed consent forms. Community involvement in research challenges the traditional models of relations between the scientific community and the populations inducted into their research. This implies a paradigm change from hierarchical structures of communication to a more egalitarian system, where community members are treated as participants and their input solicited. Much work remains to be done to sensitize scientists and researchers to this radical change in outlook.

### ***Community advisory structures matter***

One lesson that Fenway and its CAB have learned from participating in the HPTN is that CABs in sites outside of the United States are often more embedded in their communities. This means that they emphasize the necessity of focusing on urgent practical matters as well as issues linked to HIV/AIDS as part of a holistic approach. This type of structure may be useful in mobilizing communities of color in the United States. The example set by early AIDS activism has also been helpful in conceptualizing the notion of CABs.

### ***Community representatives can make a difference in the outcome of HIV prevention trials***

Fenway and its CAB are learning, as the epidemic matures, that we must all sustain our commitment and apply it to other areas of our life and work. Building community among participants increases enrollment and retention in trials and helps create a favorable impression of the research process. HIV prevention research would benefit from a larger cohort of role models and leaders, including scientists and principal investigators, who are people of color and representative of the communities from which participants are drawn. Those involved in HIV prevention research should also recruit more women, to reflect the current demographics of the epidemic.

## **References**

GMHC Web site. Available at <http://www.gmhc.org>.

UNAIDS Web site. Available at <http://www.unaids.org>.

