



Case Study: the UNITY Study

The HIV Prevention Trials Network protocol 061 is a study to determine the acceptability and feasibility of a multi-component intervention for Black men who have sex with men (MSM) and transgender (TG) women, including HIV testing and counselling, and peer health navigation, the practice of using peers to accompany participants to appropriate health referrals. At the San Francisco research site the study team called it “the UNITY Study”. The study team knew it would be a challenge to recruit more than 200 Black men and TG women locally due to a number of factors: 1) the relatively small size of the Black community in San Francisco; 2) known stigma against MSM, TG women, and HIV in the community; and 3) the well-documented reluctance of communities of colour to participate in HIV research due to distrust of the government and medical providers.

Understanding these challenges, the study team embarked on an extensive effort to engage stakeholders in the study design and execution with special attention on recruitment efforts.

The team was experienced in conducting HIV-prevention trials in San Francisco, so had some existing contacts with non-governmental organizations (NGOs) who worked with Black MSM and TG women, and who focused on HIV prevention. To meet the demands of the UNITY study, however, the site recognized that an even greater breadth of stakeholder input would be needed beyond their existing partners. The team decided to invite two members of the site’s existing Community Advisory Board (CAB) to recommend others in the Black community who should be consulted, including political, opinion, and religious leaders. The team worked with those two CAB members to contact new referrals, and, in turn, asked them for additional names. Though not all the identified stakeholders were interested or available to participate as advisors, the process laid the foundation for building relationships far into the future. The outreach process also functioned as a first step in community education, raising awareness about the research process and the objectives of the UNITY study. Those stakeholders who were interested and supportive were invited onto an e-mail list to receive ongoing information about the study, and those who were available formed the Collaborative Council. Interestingly, the Collaborative Council included many members who were largely unfamiliar to the study team. The Collaborative Council was convened before study-specific staff was hired, and offered input in every aspect of the study, including recruitment, the development of local materials and study branding (including the local study logo), and other site-specific decisions.

The Collaborative Council requested that the research be exclusive to MSM and TG women who live in San Francisco, rather than including participants from surrounding areas, such as Oakland or Richmond, which have large Black populations. Focusing on a single geographical area would help study staff create and maintain an up-to-date and relevant list of referrals for peer health navigation. The council also felt that because of the smaller Black population in San Francisco, this community was often overlooked for research opportunities, and would appreciate the chance to participate in a study focused specifically on them.



Additionally, the Collaborative Council recommended that three neighbourhood councils be formed, including community members and service-provider representatives from different regions of the city. The study team met with these councils in their own communities. During lunch meetings, these neighbourhood groups served as informal focus groups, offering substantive input into the creation of study educational and recruitment materials. The team saw that their involvement at this early stage increased their commitment to the study and its aims. In fact, in two of the neighbourhoods, the committees agreed to meet on a regular basis and assist with study recruitment and conduct.

These formative research activities were conducted over a period of about two months. The study staff presented the results back to the Collaborative Council for their reactions and analysis. The results were very rich, but a few themes stood out:

1. What most resonated with the neighbourhood committees was the study's focus on the Black community and the value of peer health navigation.
2. Community groups appeared more interested in focusing on ways to enhance overall health rather than an HIV-specific intervention.
3. There was concern that anyone who was seen responding to an advertisement for a study for MSM would be discriminated against for their sexual orientation.
4. TG women demanded messages specific to them, and not as a sub-category of men.

In response to these findings, the study team re-focused on the peer health navigation aspect of the study, so that they could offer the participants culturally competent navigation to the services that most interested them, including job training and substance-use services.

Based on stakeholder input, the biggest change involved the study recruitment materials. After much consideration, the CAB and staff decided that the materials would not contain the words "men who have sex with men," or "HIV." Rather, the campaign focused on Black pride. Three separate posters were made that contained quotes from Black community leaders aimed at affirming their beautiful Blackness and putting positive messages about being Black into the community. The words were shaped into silhouettes. The text advertised a website and number to call for a Black men's study. One of the posters was specifically designed for TG women and included appropriate language and images.

Because of the concern about stigma, only after potential participants visited the website or called the study phone line did they learn about the emphasis on HIV prevention. Study staff were concerned that this approach might feel sneaky or dishonest, but were pleased to experience a huge, positive response from the community. In addition, the neighbourhood groups felt greater ownership and partnership in the study, and participated actively in outreach efforts for the study. These efforts led to the site effectively achieving its recruitment goals and helping to answer the study's research questions.