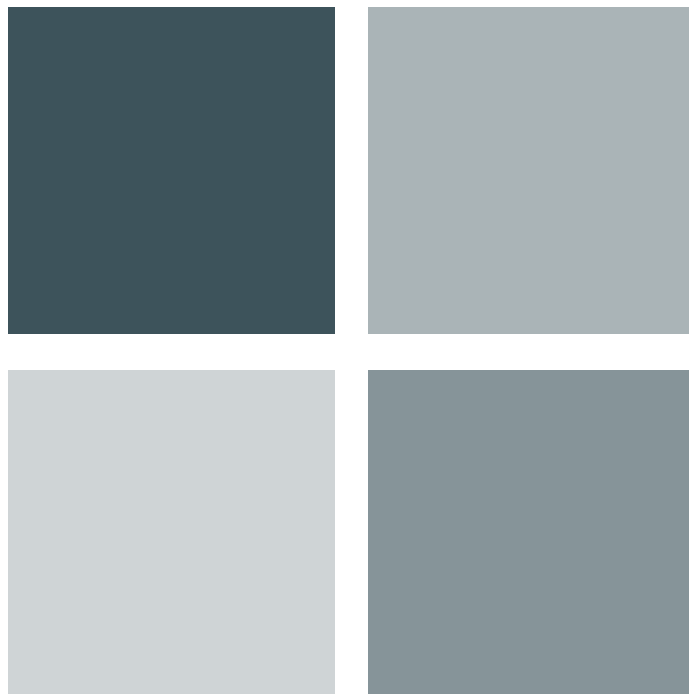


Lessons Learned from Harare, Zimbabwe



University of Zimbabwe

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U.S. Partner Institution	University of California at San Francisco
Study Populations	Women, HSV-2-positive people, HIV-positive pregnant women, infants born to women living with HIV, serodiscordant couples
Key Topics	CAB training, dispelling rumors in the community, male involvement, communication between CAB members and researchers

Introduction

Zimbabwe is located in southern Africa and has a population of nearly 13 million people. About 67 percent of Zimbabweans live in rural areas. On average, women begin to bear children between the ages of 15 and 19, giving birth to an average of four children over their lifetime.

By the end of 2003, the HIV prevalence rate of the population aged 15 to 49 was estimated at 24.6 percent, indicating that 1,600,000 Zimbabweans in this age group were living with HIV (National Aids Council 2004). Of this number 930,000, or 58 percent, were women; an additional 120,000 children under 15 were also infected with the virus (UNAIDS/WHO 2003). In urban areas, the prevalence rate among 15- to 49-year-olds was about 28 percent; in rural areas, it was about 21 percent (National AIDS Council 2004). In 1980, the estimated life expectancy at birth was about 58 years. Estimates suggest that, due to AIDS-related deaths, life expectancy dropped to the mid-30s by 2003 (*ibid*).

The HIV Prevention Trials Unit (HPTU) of the University of Zimbabwe in Harare has been working in collaboration with the University of California at San Francisco (UCSF) since 1994. The first collaboration between the University of Zimbabwe and UCSF was a prospective study to examine the health effects of intravaginal practices, such as cleaning the vagina with fingers, wiping the vagina, and inserting traditional substances to make the vagina tight (for dry sex). Subsequently, the universities conducted a feasibility study on vaginal microbicides in Zimbabwe.

HPTN Research Studies in Zimbabwe

The University of Zimbabwe and UCSF currently collaborate on 15 research studies, five of which are HIV Prevention Trials Network (HPTN) protocols. Table 4 summarizes the current HPTN protocols in Zimbabwe, in addition to a completed HIVNET study.

Table 4. HPTN Research Studies in Zimbabwe

Study #	Protocol and Purpose	Study Population in Zimbabwe	Other Sites
HIVNET 016A	<p>Condom promotion and counseling study.</p> <p>Purpose: to evaluate the effectiveness of condom promotion and counseling messages on uptake of condoms as a means to prevent HIV transmission in women attending postnatal and family planning clinics.</p>	Women attending postnatal and family planning clinics.	Blantyre and Lilongwe, Malawi
HPTN 035	<p>Phase II/IIb study of the vaginal microbicides BufferGel and 0.5% PRO2000/5 Gel (P) for the prevention of HIV infection in women.</p> <p>Primary objectives: 1) to evaluate the safety of BufferGel and 0.5% PRO2000/5 Gel (P) when applied intravaginally by women at risk for sexually transmitted HIV infection; 2) to estimate the effectiveness of BufferGel and 0.5% PRO 2000/5 Gel (P) in preventing HIV infection among at-risk women.</p>	520 sexually active, HIV-uninfected women.	Blantyre, Malawi; Durban and Hlabisa, South Africa; Lilongwe, Malawi; Lusaka, Zambia; Philadelphia, USA
NIMH Project Accept (HPTN 043)	<p>Phase III trial of community mobilization, mobile testing, same-day results, and post-testing support.</p> <p>Purpose: to test the hypothesis that communities receiving 2½ years of community-based voluntary counseling and testing, compared to communities receiving 2½ years of standard voluntary counseling and testing, will have significantly lower prevalence of recent HIV-1 infection.</p>	36,000 community members at large in Mutoko.	Johannesburg, South Africa; Dar Es Salaam, Tanzania; Chiang Mai, Thailand
HPTN 039	<p>Phase III trial of acyclovir for the reduction of HIV acquisition among high-risk HSV-2-seropositive, HIV-seronegative individuals.</p> <p>Primary objective: to measure the efficacy of twice daily acyclovir suppressive therapy in preventing HIV infection among HSV-2-seropositive, HIV-negative women and men who have sex with men at high risk for HIV infection.</p>	300 HIV-negative women who have sex with men who are infected with the herpes simplex virus 2.	Iquitos, Lima and Pucallpa, Peru; Seattle, USA; New York, USA; Lusaka, Zambia; San Francisco, USA; Johannesburg, South Africa
HPTN 046	<p>Phase III trial to determine the efficacy and safety of an extended regimen of nevirapine in infants born to HIV-infected women to prevent vertical HIV transmission during breastfeeding.</p> <p>Primary objectives: 1) to compare the rate of HIV-1 infection at six months in infants determined to be HIV-uninfected at birth in each arm; 2) to evaluate and compare the safety and tolerance in infants in each arm.</p>	100 HIV-1-infected women and their breastfeeding infants.	South Africa; Uganda; Tanzania

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Study #	Protocol and Purpose	Study Population in Zimbabwe	Other Sites
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>	HIV-serodiscordant couples in all study sites.	Blantyre and Lilongwe, Malawi; Pune and Chennai, India; Porto Alegre and Rio de Janeiro, Brazil; Chiang Mai, Thailand; Boston, USA

Community Advisory Board

In the mid-1990s, well before the University of Zimbabwe established community advisory boards (CABs) for the HPTN, several partnerships and collaborations between the university and other research and service institutions were already addressing issues such as duplication of effort, referrals, research misconceptions, and community sensitization. These were important first attempts at community involvement. Later, technical assistance in the form of training and guidance from the HPTN Community Coordination and Operations Center’s Family Health International staff led to the creation of formal CABs and more meaningful community participation in research.

Establishment

Three separate CABs have been established to serve both HPTN and non-HPTN studies in Zimbabwe. They are located in Harare, Epworth, and Chitungwiza (Mashonaland East Province). The Chitungwiza CAB, with 14 members, was established in 2000, while the Harare and Epworth CABs, with 12 and 16 members, respectively, were established in 2001. The CABs were responsible for more than one study in their communities, and protocol-specific subcommittees were also created to serve as a resource to the principal investigators and study staff. In Harare Province, eight sub-CABs have been established to help ensure representation of the interests of different community groups. However, maximum representation of the interests of various groups remains a challenge.

Other community involvement structures are currently under development in Mutoko, also in Mashonaland East Province. The community-based voluntary counseling and testing study team is preparing communities for future studies and is in the process of consulting stakeholders for suggestions about who should constitute community working groups, the study advisory committee, and the national advisory committee.

Members

Zimbabwe CAB members were recruited in a way that ensures diversity of age, gender and ethnicity. To make certain that communities were well represented in all research activities, membership was drawn from opinion leaders and key individuals representing different constituencies in the research communities. These included public health officials; representatives of various

nongovernmental, community-based and faith-based organizations; advocates and activists working on women's health and HIV/AIDS; representatives of men's organizations; legal practitioners; people living with HIV; youth leaders; political councilors; study volunteers; teachers; village community workers; traditional midwives; members of the uniformed forces; and other interested and committed community-based individuals.

Study-specific outreach workers, employed by the University of Zimbabwe-UCSF research program, played an important role in the initial recruitment of CAB members. They recommended to the community liaison director key individuals and representatives of organizations and institutions in the communities whom they believed were interested and invested in HIV prevention. The community liaison director then approached the individuals, organizations and institutions to substantiate the outreach workers' recommendations and obtain further suggestions. He also spent time in the research communities participating in community outreach activities, attending community meetings and non-HPTN training workshops to assemble more information about the communities and how they were organized. Information gathered from these different sources helped him determine which individuals to recruit. Once potential CAB members had been identified, initial meetings to discuss the concept of a CAB were convened. These meetings led to an agreement to conduct training workshops to orient the new CAB members.

The community members recommended by outreach workers readily accepted their positions, and they have proven to be dedicated and committed individuals. The majority of these volunteers, particularly in Epworth, have served their communities for the past 12 years.

Training

Three-day orientation workshops for CAB members were conducted by the University of Zimbabwe-UCSF. Topics covered included:

- Basic facts on HIV/AIDS
- Impact of the HIV/AIDS pandemic
- The HPTN and adult AIDS clinical trials group research agendas
- HPTN research ethics
- Overview of the University of Zimbabwe/University of California research program
- The role of CABs in HIV prevention research
- Research design
- Participatory methodologies in community education
- Participatory management
- How to develop a work plan
- Volunteerism
- Community activism
- How to conduct community meetings

Informal adult training methodologies included lectures, story-telling, role-plays, improvised drama, songs, and other participatory methods. In addition to the training workshops, the three CABs exchanged visits and went on learning retreats to share ideas, experiences, and best practices.

Support

During the early stages of CAB development, the Zimbabwe HPTU's administration department, the community working group core, and the HPTU's community department provided CAB members with support for beginning their work. This support included development of work plans, CAB constitutions, and codes of conduct, as well as material, financial, and moral support. Later, the CAB members received additional support to make them more effective, such as:

- Bicycles to increase their mobility (five per CAB)
- Mobile phones to improve communication (one per CAB)
- Funds to allow CAB members to attend local, regional, and international meetings
- Funds to allow CAB members to conduct exchange visits
- Funds to allow the three CABs to attend an annual learning retreat, where they share experiences and “best practices”
- Funds to convene and cover the practical costs of bimonthly meetings so that CAB members, principal investigators, and research staff can meet and deliberate on research-related issues

Community Advisory Board Activities

Once they have received training, CAB and sub-CAB members participate in a number of activities that support HPTN and other research studies in Zimbabwe. Activity categories and specific examples are listed below.

Community education and mobilization

Zimbabwe CAB members educate the community on HIV/AIDS issues. They serve as voices for communities and study participants by listening to and drawing out information on local issues or concerns that can affect the successful conduct of the research agendas. One example of these issues is local politics. In most communities in Zimbabwe, traditional political leaders (as well as the general public) require adequate information about research studies and other programs to be able to lend their support. Unfulfilled promises or failure to disseminate research results to communities can also affect the successful conduct of research. Community advisory board members alert researchers to community expectations so researchers can work closely with community advisors to address the issues and concerns.

Community advisory board members also mobilize community and political support by convening community meetings and organizing workshops in which they address different community groups, opinion leaders, and other stakeholders on issues related to the research. This creates awareness about forthcoming and current studies and helps build trust between researchers and community members. Community education is the first line of defense against misperceptions and rumors about the research process. During the early days of community entry into the Epworth and Chitungwiza communities, researchers were perceived as Satanists and political opportunists. It was through the CABs' education efforts that the communities' perceptions were transformed.

Community Advisory Board member meetings

Community advisory board members hold meetings on a bimonthly and *ad hoc* basis. In these meetings, they discuss progress made and constraints and opportunities encountered, and they suggest viable solutions to problems and issues. They also plan for and review research activities and help determine community needs, with the goal of later bringing them to the attention of researchers and ensuring that these needs are addressed. In an example of this process, members of one community requested that CAB members help create research studies that target men and not just women. As a result, the HPTN mobile community-based voluntary counseling and testing study was conducted in the community and was well supported.

Evaluation of research study impact

Another important CAB activity is evaluation of the impact of research studies on local communities. The study updates that CAB members receive during their meetings are tools that allow them to monitor and evaluate the impact of research studies in their communities. For instance, at one of the bimonthly meetings, Epworth CAB members noted and then reported to research staff that the number of people seeking HIV counseling and testing services was continuously rising, indicating that community members were supporting and at the same time benefiting from voluntary counseling and testing services. In addition, the CAB members reported that the Epworth community supported the HPTN mobile community-based voluntary counseling and testing study because it brought a needed service to the community as opposed to the traditional practice where people seek the service elsewhere.

Review of study materials: protocols, consent forms, posters, and leaflets

Community advisory board members also participate in the review of study materials, including protocols, consent forms, posters and leaflets. Through this activity, they aim to ensure that research is conducted ethically and with input from the communities.

Recruitment and retention of study participants

Community advisory board members provide advice on issues regarding recruitment and retention of study participants. They assist in identifying groups of potential study participants and convene meetings where outreach workers (responsible for participant recruitment and retention) present the study and answer questions about participation. Zimbabwe's CAB members have provided guidance on what to include in the participant locator form to ensure better participant retention and follow-up. They have also recommended community-wide education on the importance of volunteering to participate and remain in the research studies.

Community dissemination meetings

Zimbabwe CAB members hold community meetings in which they disseminate study information and outcomes of specific studies. They recommend community groups, stakeholders and opinion leaders who should attend the dissemination meetings while emphasizing the principle of confidentiality. Meeting attendees later disseminate results to their constituencies and peers. They also advise researchers on the most effective and comprehensive ways of presenting the study results to the communities, including the use of simple language.

Challenges

The Zimbabwe CABs faced a number of challenges in their work.

Gaining entry into and acceptance from the communities

Gaining entry into and acceptance within the communities in which the research took place were challenging initial priorities for the CABs. Community advisory board members and principal investigators met with relevant authorities at various levels, such as Minister of Health and Child Welfare; provincial and district health and political authorities; and provincial and district representatives of different governmental and nongovernmental agencies in the research communities. The district leadership — namely district administrators, district police officers, councilors, district AIDS action committee chairpersons, district nursing officers, and representatives of NGOs — then helped sensitize their constituencies to the HPTU research agendas. Sensitization also occurred through monthly stakeholders' meetings organized by the district AIDS action committee.

Facing the distrust of community leaders

In the beginning, many community leaders, especially political leaders, were skeptical and suspicious of the intentions of the CABs and research studies. Some thought that research staff sought to usurp their power by working with and gaining the support of people in the community. Some opinion leaders even suggested that when doing fieldwork, the researchers needed to be accompanied by community advisors to monitor their activities. Community education strategies such as workshops and community meetings with important leaders were employed to address their misconceptions and skepticism. Greater involvement of the community leadership in research processes and talks given by the Minister of Health and Child Welfare at special annual events (such as University of Zimbabwe-UCSF Research Day which credited the University of Zimbabwe-UCSF team for its role in HIV prevention) also helped build trust between community leaders and the research institution.

Representing the diverse communities within Harare

Due to the widely diverse constituents in the communities within Harare, the CAB had difficulty representing the many different viewpoints, concerns, and needs of the various groups. To better represent the different sectors within Harare, eight cluster CABs (also known as sub-CABs) composed of five members each, were established to include as many different community concerns and viewpoints as possible. These sub-CABs identify the needs and the concerns of the groups they represent and then bring them to the attention of the main CAB (also known as “the Whole”) and the researchers. Sub-CABs interact with many communities, for example, churches, the uniformed services, and youth forums. While this has helped somewhat, adequate representation remains a challenge due to the continuous emergence of new communities of interest.

Correcting misconceptions and dispelling rumors about the research

As with many new research studies, misinformation and suspicions were a challenge after the Zimbabwe studies began. A few community leaders in Chitungwiza and Epworth, who felt that the studies threatened their power, propagated the idea that the research was satanic. To confront these rumors, the CAB assisted with education efforts to inform communities about the nature of research and to involve community leaders in research processes, such as reviewing study protocols,

consent forms, posters, brochures, leaflets, and participant reimbursement amounts. The CAB also sought their advice on recruitment and retention of study participants and encouraged community leaders to visit research sites to talk with research staff.

Educating the communities about research

In general, most communities knew very little about the concept of research, its terms, or its goals. Educating communities about research goals and concepts such as “protocols,” “control groups,” and “randomization,” is always a challenge for CABs and community educators. The CABs and sub-CABs assisted in identifying useful ways to present these concepts to the communities. They organized workshops on how to use local language to educate opinion leaders about research. To reinforce the lecture method, improvised drama followed, in which some research staff members dramatized all the stages and procedures in collaborative research. Topics included identifying the community’s health problems together with opinion leaders, designing research, seeking community entry, community mapping, creating awareness about the study, fostering partnerships, roles and responsibilities of community advisors, recruitment and enrollment of study participants, follow-up and associated procedures, and dissemination of study findings. Songs that captured the essence of HIV prevention research and collaboration were composed and sung during the workshops.

Identifying CAB members and maintaining morale

Identifying and retaining productive CAB members is always a challenge. While most members performed well, several agreed to join the CAB only because they thought they could gain formal employment with the University of Zimbabwe-UCSF HPTU. When they were not hired, they quickly left the CAB, and new members needed to be identified. To identify dedicated and committed CAB members, research staff no longer rely solely on recommendations made by outreach workers and key opinion leaders. Research staff now conduct rigorous interviews and include an experienced CAB member on the interview panel.

CAB members’ morale was and remains a major challenge. Economic hardships in Zimbabwe have had a negative effect on the spirit of volunteerism among most people in the communities. Volunteers often express feelings such as, “It’s time to go home and engage in petty-trading, otherwise my family will suffer.” To maintain morale for the volunteers, the research studies continue to provide training, retreats, allowances to meet basic meeting costs, T-shirts, hats, and bags. Attendance at regional and international meetings is also sponsored for some CAB members. However, much more needs to be done to bolster volunteer morale.

Lessons Learned

The HPTN partnership between the University of Zimbabwe and the University of California at San Francisco and the experience of the Zimbabwe community advisory boards have produced the following lessons.

All relevant stakeholders should be informed about the research before a study begins

All relevant stakeholders from the national level down to the community level should be effectively mobilized and well informed about the research before it begins. This is the first and most important step in gaining the community's support and trust. Key stakeholders include opinion leaders; members of faith-based organizations, nongovernmental organizations, community-based organizations; representatives from the public and private sectors and the media; and other community members. In Zimbabwe, meetings between CAB members and principal investigators and all levels of government authorities, nongovernmental and community-based organizations, and community leaders were key to mobilizing support for HPTN research.

Community advisory board members must receive adequate training and empowerment, including tools to keep their constituents informed and supportive of the research

Community advisory board members need to learn as much as possible about research protocols and the basic concepts of research so that they can inform stakeholders and their constituents, answer questions from the community, and address any problems that arise, especially problems caused by misinformation. The workshops that CABs and research staff organized to explain research concepts and structure to communities were instrumental in empowering both CAB and other community members. The use of creative methods, such as dramatization and song, was particularly effective in presenting this information.

Community representatives can make a difference in the outcome of HIV prevention trials by effectively mobilizing their communities

HPTN trials in communities with effective CABs generally run more smoothly and generate useful research results. Communities are happier when they are informed and feel that CAB members are looking out for their interests. Conversely, if CAB members are not engaged, or if they are identified too closely with researchers' objectives (i.e., they are considered study employees), community members may view the studies with suspicion and spread misinformation that can hamper participant recruitment and jeopardize community trust and support.

In Zimbabwe, training workshops for CAB members and research staff helped both teams gain a greater understanding of community involvement issues such as joint planning, consultation, collaborative research/partnership, respect for other people's ideas, trust, and CAB members' autonomy. Despite the existence of productive collaboration between CABs and research staff, CAB members have managed to maintain their independence from researchers in a number of ways. They organize their own meetings to discuss or review study protocols and other research materials, and then they

give their recommendations. They have raised concerns that some questionnaires are too long and have recommended breaks in between interviews. They have also challenged researchers to develop studies that target men and not just women.

Community advisory boards can make a valuable contribution to research methodology and design

Innovative CAB members can help develop and test new strategies to promote community participation. In the Epworth and Chitungwiza communities, CAB members are now promoting dialogue on issues that fuel the spread of HIV, such as gender-based inequalities. In addition, participatory action research is helping confront the challenge of actively involving males in HIV prevention efforts. This research has included such methods as storytelling and small-group discussions. In a workshop to generate ideas for participatory action research on male involvement in HIV prevention, participants (including some CAB members) told stories that highlighted gender inequalities and strategies to deal with them. In small-group discussions participants explored the significance of and reasons for male involvement in HIV prevention and the kinds of actions men can take at individual, family, social, and community levels to support women and make a difference in the fight against HIV/AIDS. The male involvement outreach team is now addressing men in churches, beer halls, and at burial societies and ward political meetings organized by the Epworth community political leadership.

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