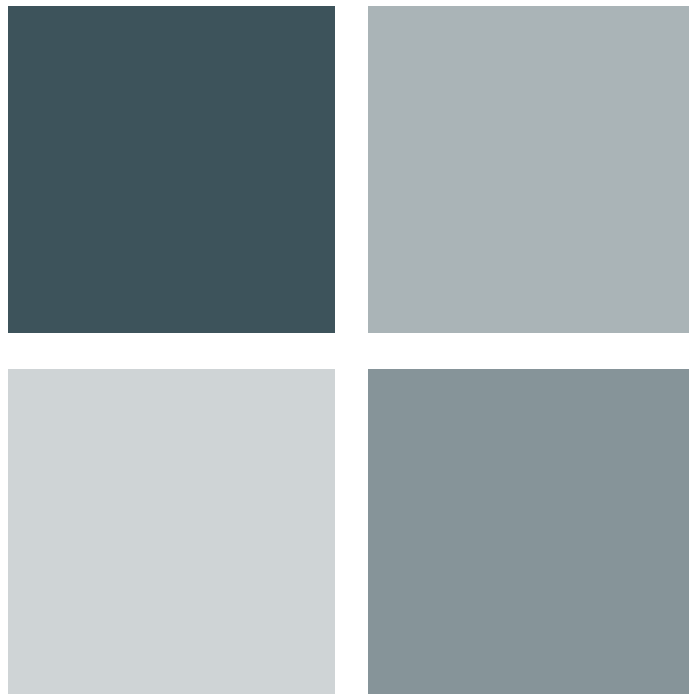


Lessons Learned from Dar es Salaam, Tanzania



Muhimbili Medical Center Temeke District Hospital

Article Author	Wandoa Mwambu, Dip. Ed., community educator
U.S. Partner Institution	Harvard University School of Public Health
Study Populations	Pregnant women living with HIV, infants born to women living with HIV
Key Topics	Community drama, educational entertainment, community sensitization, male involvement

Introduction

Tanzania is situated on the east coast of Africa, includes the island of Zanzibar, and has a population of 36 million people. The Dar es Salaam region, the nation's capital district, is the smallest of 21 regions but hosts a population of nearly 2,500,000 people, or 6.4 percent of the national population. In Tanzania, the transmission of HIV is predominantly heterosexual (78 percent of all HIV cases), with higher infection rates among women. The overall HIV prevalence rate among people aged 15 to 49 is currently estimated at 7.7 percent among women and 6.3 percent among men, numbers that result in some 70,000 new infections each year in Tanzania. By the end of 2003, 1.6 million people were estimated to be living with HIV in Tanzania, including 100,000 children under 15. In Dar es Salaam, estimates suggest that 12.2 percent of women aged 15 to 49 are HIV-positive, while an estimated 9.4 percent of men in the same age group are living with the virus. The higher rates of HIV infection among women have important implications for mother-to-child HIV transmission (UNAIDS 2004).

In Dar es Salaam, the Muhimbili Medical Centre and Temeke District Hospital together form the HIV Prevention Trial Unit (HPTU).

HPTN Research Studies in Tanzania

Tanzania has hosted three HIV Prevention Trials Network (HPTN) research studies. These include HPTN 024, which was halted by the Data Safety Monitoring Board before the end of the accrual period, when the data showed that the antibiotics did not further reduce chorioamnionitis-related mother-to-child transmission of HIV. Since study subjects understood through the informed consent process that the trial could stop at any time, halting the study did not have significant adverse effects on the community. Two additional studies are currently taking place in Tanzania: HPTN 046 in Dar es Salaam and HPTN 055 in Moshi. Table 2 contains additional details about the Tanzania HPTN studies.

Table 2. HPTN Research Studies in Tanzania			
Study #	Protocol and Purpose	Study Population in Tanzania	Other Sites
HPTN 024	Phase III trial of antibiotics to reduce chorioamnionitis-related perinatal HIV transmission. Purpose: to determine if low-cost antibiotic treatment given twice during pregnancy and aimed at reducing chronic and acute chorioamnionitis will reduce perinatal HIV transmission.	780 HIV-positive pregnant women; to prevent stigmatization and investigate the impact of antibiotics on HIV-negative women, 200 pregnant HIV-negative women were enrolled and treated in the same way as the HIV-positive women.	Blantyre, Malawi; Lilongwe, Malawi; Lusaka, Zambia
HPTN 046	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. 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 (nevirapine vs. placebo); 2) to evaluate and compare the safety and tolerance in infants in each arm.	1,576 HIV-1 infected women and their breastfeeding infants in all sites.	South Africa, Uganda, Zimbabwe
HPTN 055	HIV prevention preparedness study. Primary objective: to estimate rates of HIV sero-incidence among women targeted for inclusion in HPTN 035.	240 sexually active HIV-uninfected women aged 16 to 49.	Durban and Hlabisa, South Africa; Lusaka, Zambia

Community Advisory Board

Establishment

The Dar es Salaam community advisory board (CAB) was established in May 2001 by a steering committee comprised of investigators implementing HPTN study 024. Representatives of community-based organizations involved in HIV/AIDS care and support activities also participated in the CAB creation. The election team gave careful consideration to forming a CAB with a diverse, representative membership.

Members

Voting CAB members included representatives of local HIV/AIDS nongovernmental and community-based organizations, an artisan, a nutritionist, teachers, traditional birth attendants, and people living with HIV/AIDS. *Ex officio* nonvoting members included the district AIDS control coordinators from the three districts of Dar es Salaam, who represented their health departments. Later, the multisectoral

municipal AIDS control coordinators of the three districts, who represented all administrative sectors of the local government, replaced the district coordinators. Other nonvoting members included representatives of the research project (the study's nurse coordinator and a project administrator). The ratio of direct stakeholders to indirect stakeholders among voting CAB members was on average 1:5. The number of CAB members varied from 14 to 16, and their term of office was set at three years.

The Dar es Salaam CAB currently has a well-equipped office and is considering establishing a sub-CAB to address issues in the Temeke District, where a satellite Muhimbili Research Clinic is now in place.

Training

Dar es Salaam CAB members receive orientation training and participate in Africa Regional Working Group training workshops. The Dar es Salaam CAB also sends representatives to the HPTN Africa General Meeting and national and regional HIV/AIDS conferences.

Community Advisory Board Activities

The Dar es Salaam CAB meetings bring together all voting and *ex officio* CAB members on a monthly basis. The agenda of these meetings includes planning for mobilization, sensitization, and community meetings involving community leaders, child-bearing women, and men. Members review and follow up on issues raised in the community, and make and discuss suggestions with the research team for improving recruitment and retention of participants. Community advisory board members also receive reports from research operations meetings through the community educator, who represents the CAB at these meetings. During CAB meetings, nurse counselors report on issues of concern from operational meetings; these issues often provide material for community drama activities.

Another focus of the Dar es Salaam CAB has been training and community sensitization activities. At the beginning of HPTN 024, the Dar es Salaam HPTU and CAB convened community and religious leaders in each of the three municipalities of Dar es Salaam for a day of sensitization training. Leaders received information designed to sensitize them to issues related to vertical HIV transmission, with the desired end result that they would allow and encourage people of child-bearing age to seek voluntary HIV counseling and testing. A total of 117 leaders participated in CAB sensitization activities. Follow-up meetings took place in the Kinondoni Municipality. These follow-up meetings generated tasks for the CAB to support local government offices at the ward level. Among these tasks was the identification of specific needs at the ward level for undertaking community mobilization with ward executive secretaries for the prevention of mother-to-child HIV transmission. Identified needs included:

- Facilitating training for development of information, education and communication materials
- Facilitating training in mapping of study clinic catchments for community drama, to allow for the use of “edutainment” (educational entertainment) for community education
- Conducting workshops for community mapping and assisting local government leaders in prioritizing the mapped areas for community sensitization

The HPTU and CAB trained religious leaders about vertical transmission of HIV in hopes they would encourage people to seek counseling and testing.

The Dar es Salaam CAB was also centrally involved in conducting awareness campaigns on the prevention of mother-to-child HIV transmission during the annual International Trade Fair in Dar es Salaam in 2002, 2003 and 2004. Community advisory board members facilitated a 10-day mass prevention campaign, using an approach consisting predominantly of edutainment to draw crowds to booths where information was available on prevention of mother-to-child HIV transmission and other preventive services. The CAB estimates that it reached approximately 60,000 people with prevention messages. HIV counseling and testing services were available at the booths during two of these years, in collaboration with the Muhimbili Health Information Centre. A total of 1,869 people received counseling and testing at the booths; 81 people tested HIV-positive.

The CAB in Dar es Salaam has participated in the documentation of ward-facilitated community drama activities through the use of CAB outreach peer educators. The CAB estimates that 17,806 residents in selected mapped areas of Kinondoni Municipality attended the community drama events. They included 5,302 males and 8,240 females. Specific drama activities for young people reached 4,264 youths. The effects of communicating the core messages are documented in study clinic data, as outlined in the box below.

Community mobilization: Kinondoni Municipality, Dar es Salaam

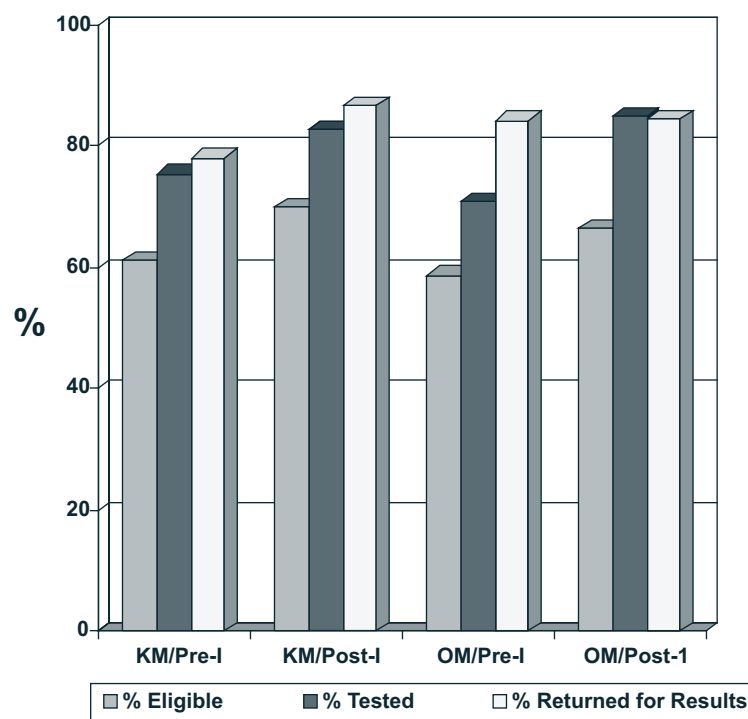
In September 2002, local government teams conducted community mobilization activities in wards of the Kinondoni Municipality (KM). The activities involved use of community drama in mapped localities to raise awareness about mother-to-child HIV prevention and to stimulate community action using three key messages: 1) early booking for antenatal care; 2) uptake of voluntary HIV counseling and testing services offered in antenatal care facilities; and 3) male involvement in antenatal care.

Accrual data from antenatal research clinic sites were assessed seven weeks before the community mobilization activities in both Kinondoni and other municipal (OM) study recruitment antenatal clinics (in July and August 2002). Women eligible for the study numbered 923, or 61 percent of all booked women in the Kinondoni sites and 511, or 59 percent of all booked women in the other municipality sites. These data were compared with similar data collected for seven weeks after the community mobilization activity in the Kinondoni catchments served by study clinics (in October to November 2002). Data were based on 1,403 study-eligible women, or 70 percent of all booked women in the Kinondoni sites and 551, or 67 percent of all booked women in the other municipality sites. The rates for eligibility, consenting to HIV testing, and returning for test results are summarized in Figure 3.

In both the Kinondoni and other municipality clinics, there was an increase in the proportion of study eligible women attending the clinics. A higher proportion of eligible women consented to HIV testing after the community intervention in the Kinondoni and other municipality clinic sites, as opposed to before the intervention. In the Kinondoni site, as compared to other municipality sites, there was a significant increase in absolute numbers of women eligible for the trial, suggesting previous noneligibility may have been participants' way of not consenting. There was also a post-intervention increase in the proportion returning for HIV test results in the Kinondoni sites, compared to baseline rates.

Conclusion: Community mobilization activities in Kinondoni may, in the short term, have increased the number of women who agreed to participate in the trial and who returned for HIV test results.

Figure 3. Percentage of Women Who Were Eligible for the Study, Who Agreed to Test, and Who Returned for Results



KM = Kinondoni Municipality; OM = Other Municipality sites

In June 2004, the Dar es Salaam CAB hosted the HPTN Community Africa Regional Working Group Training Workshop. The main topics presented were an overview of the Muhimbili University College of Health Sciences – Harvard School of Public Health collaborative research projects, “Male Involvement in Prevention of Mother-to-Child HIV Transmission,” “Stigma and Discrimination,” and an introduction to research study design. Community CORE staff members from Family Health International also facilitated a research ethics training workshop for CAB members.

Community involvement activities at the Dar es Salaam site began just after the establishment of the CAB steering committee. The CAB decided early on that there was a need for activities aimed at enabling communities to understand the HPTN research agenda.

UNICEF had earlier piloted and refined the use of community drama for health education purposes in Tanzania. The CAB, therefore, included an artist in its membership to provide support for use of this communication method in the communities that would be served by study clinics. As a result of this approach, the Dar es Salaam CAB has developed a working relationship with some community-based drama groups. The initial activities involved provision to communities of very basic information about the research process, using simple language in skits, songs and traditional performances. The community drama approach also allowed for presentation of

problematic issues (such as male involvement and providing incentives for women to access clinic services early in pregnancy) and getting feedback from the community. Drama groups developed themes of problematic areas identified by the research team and presented them to communities to facilitate discourse on the problem at community level. Drama has also been useful in presenting the problem and getting feedback on community views.

The CAB developed a position for a community outreach peer educator, whose role was to help document the process of community-based drama and to assist ward executive secretaries with community mobilization activities. This approach proved to be very productive during the lifetime of the antibiotic trial to reduce chorioamnionitis-related HIV transmission, and the CAB hopes to continue using a community drama approach for community education.

The Dar es Salaam CAB was able to gain entrance into and acceptance of communities through collaboration with and support from community (local government) and religious leaders. This collaboration was the outcome of:

- Carefully identifying relevant community and religious leaders in each district
- Conducting sensitization seminars with identified community and religious leaders in each district
- Having a pre-planned follow-through of ideas and strategies raised in sensitization seminars, facilitated by:
 - identifying specific community leaders in each study clinic catchment area as contact people for follow-up
 - conducting sensitization meetings with community leaders in each study clinic catchment area (with follow-through meetings for agreed-upon actions)
- Facilitating community mobilization activities planned and conducted by community leaders
- Facilitating training of community leaders to allow for mapping of study clinic catchment areas for community drama (edutainment) activities

Community leaders responded to emerging issues by identifying concerns within the research catchment areas. Examples include:

- Male involvement in antenatal care — observation shows that more men are currently accompanying their partners to antenatal clinics. The challenge is to ensure that antenatal clinics are properly prepared to attend to male clients.
- Early booking for antenatal care — this was a focus of many of the community drama activities, as late booking was presented as a major problem across all three districts.
- Nutrition — leaders pointed to specific issues of nutrition and infant feeding, regardless of HIV status, as a particular area of concern. The CAB transmitted this information to the research team, resulting in research nutritionists conducting specific counseling on nutrition in study clinics.

Community Advisory Board Roles in Research Methodology

The Dar es Salaam CAB was established after the protocol for HPTN 024 was developed. At the time, CAB members felt that they needed more orientation on the protocol to be effective in the tasks ahead of them. During preparations for implementation of the HPTN 046 protocol, the CAB

was centrally involved in reviewing translations of study instruments, particularly consent forms, to ensure that potential study participants would understand the language. A CAB representative attends the weekly HPTU operational meetings. In this way, the CAB participates fully in reviewing forthcoming plans and providing suggestions to the research team.

The Dar es Salaam CAB is involved in sensitizing populations in the catchment areas of recruitment clinics and often uses information on clinics with low accruals as an indication that it needs to explore potential barriers to participation. These barriers have typically included women requiring permission from their partners to undergo HIV testing or to visit the clinic early in their pregnancy. The weekly accrual report has been very useful in identifying problem areas that the CAB can address, such as lack of information in a community. The report also helps identify specific misconceptions, such as the belief that a woman living with HIV cannot give birth to an HIV-negative child, or the false notion that an HIV-positive woman who gives birth to a child by cesarean section will not recover from the delivery.

During follow-up phases of studies, the CAB identifies problems that may arise for study participants or clinic staff. One problem has been that participants want to go up-country (outside of Dar es Salaam) for delivery, even if they have been told to deliver at the research hospital. Clinic staff members have also had difficulty locating participants when they change their residence, and so lose them to follow-up. Problems like these are used to create thematic areas for development of drama skits in community edutainment activities.

The CAB provides general feedback to the research team in two ways: through the community educator, who attends weekly operational meetings, and through the principal investigator. Both are *ex officio* CAB members and sit in on all monthly CAB meetings.

The Dar es Salaam CAB facilitates community participation in research activities through:

- Planning, developing and disseminating information, education and communication activities for prevention of mother-to-child HIV transmission
- Advocating for planning and budgeting for HIV prevention at ward levels of the local government
- Using the participatory rapid appraisal approach to reinforce community commitment and ownership of activities for prevention of mother-to-child HIV transmission
- Developing and using traditional media (song and drama) to convey educational messages
- Actively participating in HIV/AIDS-related activities and other national and international events, such as World AIDS Day, national AIDS conferences, international trade fairs, HPTN Africa Regional Working Group meetings, and annual HPTN general meetings

During these events, the CAB informs community members about its activities to prevent mother-to-child HIV transmission, and conducts mass campaigns against HIV/AIDS in collaboration with other national stakeholders under the Ministry of Health, National AIDS Control Program and the Tanzania AIDS Commission.

In Dar es Salaam, voluntary counseling and testing is one of the key messages of all HPTN outreach programs for women.

The Dar es Salaam CAB is now preparing to participate in the HPTN 046 protocol. Activities will include development of the protocol, increasing the proportion of direct stakeholders among voting members, developing more formal terms of reference for CAB membership, establishing criteria for changing membership status, and developing criteria for identifying CAB partners in the community. The CAB will also use multisectoral municipal AIDS control coordinators as an entry point into communities.

Challenges

The Dar es Salaam CAB has faced some challenges in its efforts to mobilize and educate communities for HIV prevention research. Several factors linked to interacting with study participants and the community have impeded the effectiveness of research work:

- Poverty, which disrupts the uptake of activities to prevent mother-to-child HIV transmission
- Low HIV-status disclosure rates in perinatal populations
- Stigma associated with HIV infection
- Too few antenatal clinics to cater to the city population, leading to overcrowding at clinics
- Traditions and attitudes that prevent the uptake of interventions, such as the requirement of breastfeeding and condom use

Additional challenges fall into the following categories:

Creating and empowering effective community-level structures to respond to HIV/AIDS

While national policy supports the need for community-level local government bodies to engage in HIV prevention activities, frameworks for multisectoral initiatives in the Tanzanian context are in their infancy, and supporting structures are either not in place or are weak. The Tanzania AIDS Commission, for example, a national body that implements HIV/AIDS activities in the community, has formed AIDS committees at the grassroots level. However, despite enormous improvements in the structural response to the HIV epidemic in Tanzania, this effort is still preliminary, and a great deal of work remains to be done to make it as efficient as it might be. In its second triennium, the Dar es Salaam CAB hopes to work more closely with local government on initiatives to develop sustainable strategies for community-level actions in mother-to-child HIV prevention.

Maintaining effective community advisory structures

Challenges faced in maintaining effective community advisory structures include the fact that there are few full-time staff supporting CAB activities. Also, membership is voluntary, and many voting members are occupied with other activities essential to their livelihood.

Establishing other structures to engage the community

The Dar es Salaam CAB has worked to establish additional formal structures designed to engage the community. For instance, a group of 25 women living with HIV/AIDS were discharged as participants of a vitamin trial to prevent mother-to-child HIV transmission. At the end of the study, the women, who were members of a self-help group for pregnant women living with HIV/AIDS,

decided to continue meeting and, with the help of the CAB, registered their group as an official nongovernmental organization. This organization is called “WATUMAINIO,” an acronym for “Women and Children Living Positively with HIV/AIDS.” WATUMAINIO members sensitize the community on HIV/AIDS, conduct home visits, provide care for other women, and volunteer as lay counselors in providing psychological support and hope to women receiving services to prevent mother-to-child HIV transmission. They plan to address the need for economic independence by developing income-generating activities based on handmade items.

Lessons Learned

The Dar es Salaam CAB has learned some significant lessons through its work on HPTN research studies.

Communities can identify effective strategies to prevent mother-to-child HIV transmission

In Tanzania, the CAB and research team found that, with support, communities at ward level were able to develop effective activities to prevent mother-to-child HIV transmission. One example of these activities was the decision among women participating in one study to form “post-HIV-test groups.”

Voluntary HIV counseling and testing is the first step in preventing mother-to-child HIV transmission

Voluntary HIV counseling and testing in the context of prenatal care should be the first recourse in preventing mother-to-child HIV transmission. In Dar es Salaam, one of the key messages of all HPTN outreach programs was for women to take part in voluntary counseling and testing. It is now the standard procedure in all maternal care clinics to counsel and test all consenting pregnant women, as part of the Tanzania Ministry of Health program to prevent mother-to-child HIV transmission.

Community involvement in research is essential to strategies to prevent HIV transmission

In Tanzania, community involvement has been instrumental in the uptake of HIV counseling and testing and in adherence to strategies such as consistently implementing infant-feeding choices. Community participation in research led to reduced stigmatization of people living with HIV, which encouraged people to seek HIV counseling and testing and to return for their results. Community involvement was also significant in the establishment of community-based HIV counseling and testing centers. In the case of infant-feeding choices, the Dar es Salaam CAB’s efforts to sensitize communities to this issue led to more men choosing to be tested along with their female partners and wanting to know the HIV status of their babies. For women to adhere to the infant-feeding choices they make, they need economic support from their partners and a supportive environment within the community.

Community involvement facilitates identification of local barriers to HIV counseling and testing and other interventions

The Dar es Salaam CAB helped identify potential barriers to participation in the Tanzania HPTN studies through its sensitization efforts within the target community. Addressing barriers such as the

need to procure men's permission for their female partners to undergo HIV testing and to visit the clinic early in their pregnancy helped improve the implementation of the research studies.

Researchers should develop a broader vision of community involvement and participation in prevention of mother-to-child HIV transmission

In Tanzania, researchers and CAB members found that looking beyond the immediate research question helped achieve research goals. For example, in the context of HPTN study 046, the issue of male involvement has proven critical in retaining female study participants. In most of Africa, a child belongs to the whole clan; it is not possible to deal with the mother and the infant while ignoring other people involved in the child's life.

Links with community leaders help CABs and research staff reach the rest of the community

In Dar es Salaam, CAB members and researchers found that it was not possible to enter the community without first addressing the traditional community leadership. Strategies included sensitizing and involving district medical officers and heads of different religious organizations in the effort to reach the larger community for research efforts.

Planning, developing and disseminating information/education/communication materials about preventing mother-to-child HIV transmission should be an ongoing part of research activities

The Tanzania experience has demonstrated that communities are more willing to participate in planning and developing beneficial prevention initiatives and to support research activities when they receive information on key issues related to research goals. One of the most notable examples of this strategy was disseminating information in the community about how and why women living with HIV can give birth to HIV-negative babies.

Local governments can contribute to information/education/communication materials on prevention of mother-to-child HIV transmission

In Dar es Salaam, the municipal AIDS coordinators of Kinondoni Municipality are *ex officio* CAB members and are involved in the process of developing materials for audiences with low literacy. These coordinators help pretest the materials in various catchments within the municipality before final production. District coordinators have more autonomy when they review, endorse, print and disseminate such materials themselves for use outside of medical clinics.

Community- and district-level review committees should have the autonomy to review and disseminate widely accepted HIV prevention messages within the community

Review committees at the community and district level should be in charge of reviewing materials and disseminating them to communities to contribute to the scientific ethical review processes. In Dar es Salaam, the process of gaining approval of widely accepted HIV prevention messages (for use on T-shirts and kanga wraps on World AIDS Day) took a long time. General HIV messages that are not too specific to the research agenda are also necessary for continuous sensitization, even when there is no active protocol in a specific community.

A participatory rapid appraisal approach can help reinforce community commitment to and ownership of activities to prevent mother-to-child HIV transmission

In Tanzania, after using the participatory rapid appraisal approach, community leaders incorporated formulated messages about prevention of mother-to-child HIV transmission into their agendas and programs.

Traditional communication media (dance, song and drama) can convey educational messages and simplify the complicated research agenda for broader community understanding

In the context of the HPTN studies in Tanzania, CAB members and researchers found that when they used lectures to convey important research messages, audience members became bored and did not ask questions. Folk media have since proved more successful in conveying the same messages to large audiences. In Kinondoni Municipality and during the International Trade Fair, the use of traditional dance, songs and drama entertained and engaged the audience, who then asked questions about the research goals.

Male involvement in reproductive and child health care is a missing link in current research on preventing mother-to-child HIV transmission

The Dar es Salaam HPTN experience plainly showed that male involvement was essential to the success of research efforts that focused on preventing mother-to-child transmission. Efforts to sensitize men led to higher numbers of women requesting HIV counseling and testing and continuing to participate in research studies. More people are recognizing the need for male involvement in the context of family planning services, antenatal care clinics and community meetings.

Focused community awareness and mobilization activities can improve uptake of interventions to prevent mother-to-child HIV transmission and increase accrual of participants to related studies

In Dar es Salaam, mobilization activities based on the method of community drama encouraged women in clinics of the Kinondoni Municipality and other districts to consent to voluntary HIV counseling and testing, to return for their HIV test results, and to consent to participation in the HPTN study.

