TECHNICAL REPORT

Empowering community groups to support access and retention in HIV care in Muheza, Tanzania

MAY 2015

This report on the community linkages pilot intervention in Muheza District of Tanga Region, Tanzania, was prepared by University Research Co., LLC (URC) for review by the United States Agency for International Development (USAID) and authored by Joshua Kimaro, David Kihwele, Kim Stover, Ram Shrestha, Davis Rumisha, and Kate Fatta of URC. The community linkages pilot was implemented under the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project, which is made possible by the generous support of the American people through USAID, with funding from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR).

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Acknowledgements

This report describes an application of the Community Health System Strengthening (CHSS) model developed by the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project with funding support from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the United States Agency for International Development (USAID). The CHSS model is now being used in several countries in the world and in various areas of community health service provision, with promising results.

Acknowledgement is gratefully made to the stakeholders who have helped in applying this model. The authors gratefully acknowledge the valuable contribution of concerned authorities who supported materially and morally the process of introducing this model to the communities of Mkuzi and Kilulu wards in Muheza District of Tanga Region, Tanzania. Deep appreciation is due to Regina Kyauka, the Muheza District Home-Based Care Coordinator, Fauster Sulle, the nurse in-charge of Care and Treatment Clinic data, Margreth Chambo, the overall in-charge of Kilulu Dispensary, Dr. Methew Mganga, the Muheza District Medical Officer, Dr. Rehema Lymo, the in-charge of Mkuzi Health Center, and their respective teams and to the staff of Kilulu Dispensary, who painstakingly applied the model and provided valuable inputs during implementation.

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For more information on the work of the USAID ASSIST Project, please visit www.usaidassist.org or write assist-info@urc-chs.com.

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Acronyms

ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral drugs
ASSIST	USAID Applying Science to Strengthen and Improve Systems Project
CHMT	Council Health Management Team
CHSS	Community Health System Strengthening
CHW	Community health worker
CTC	Care and Treatment Center
HBC	Home based care
IP	Implementing partner
LTFU	Loss to follow-up
MAC	Multi-sectoral AIDS Committee
MOHSW	Ministry of Health and Social Welfare
PEPFAR	U.S President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV
QI	Quality improvement
RHMT	Regional Health Management Team
URC	University Research Co., LLC
USAID	United States Agency for International Development
WHO	World Health Organization

EXECUTIVE SUMMARY

Introduction

The USAID Applying Science to Strengthening and Improve Systems (ASSIST) Project supports the Ministry of Health and Social Welfare (MOHSW) in Tanzania to improve the quality of HIV/AIDS care through innovative approaches to maximize access and retention and achieve better client-level outcomes country-wide. In early 2014, ASSIST, with support from the U.S President's Emergency Plan for AIDS Relief (PEPFAR) began the Community Linkages activity in five villages of Muheza District of Tanga Region in Tanzania, building on existing work at the facility level to increase retention in the HIV continuum of care. The Community Linkages component aimed to improve retention in care for people living with HIV (PLHIV) by increasing linkages between health facilities and communities. The specific objectives of this activity were to pilot a community-based model to improve communication and linkages between health facilities and different types of community structures; to improve follow-up and referrals of PLHIV from the community to the health facilities and vice versa; and to decrease loss to follow-up of PLHIV.

Before ASSIST began supporting this activity, our situation analysis found that the government home-based care (HBC) volunteers who lived in the communities were the major link between the facility and the community. HBC volunteers were responsible for covering 20-25 households but reported that they often felt overwhelmed and that they could not reach every household with the information they were supposed to be providing. HBC volunteers could not physically track all lost to follow-up patients due lack of transport and other logistical support. Health facility staff interaction with the communities was limited to clinic visits, community campaigns such as immunization, and through the HBC volunteers. This resulted in low uptake of HIV services by PLHIV due to a lack of understanding of the benefits of care, an ineffective referral system, poor follow-up, and a high rate of patient loss to follow-up. To get patients to come back to treatment, the health facility staff tried phoning them, but this had not worked well.

Intervention

ASSIST engaged community groups to support the work of HBC volunteers to improve access to HIV/AIDS services and retention in care in their villages using the Community Health System Strengthening (CHSS) model. The CHSS model contributes to the PEPFAR 3.0 strategy by improving the performance of community-based health workers and increasing linkages between communities and health facilities to improve HIV prevention, treatment, and care, thus contributing to morbidity and mortality reduction. The CHSS model was thought to be a promising strategy in Muheza, where rural communities, though possessing limited material resources, have their own informal health and social welfare systems where community members make decisions and work together to improve the health of community members and the general welfare of the community. The basic concept of the CHSS model is to bring together representatives from all of these groups, the facilities, and local government to constitute a community improvement team that can identify local HIV and health gaps and develop and test locally feasible strategies to bridge those gaps.

In each of the five villages, the community improvement team was composed of a village government leader who had gone through the orientation course by ASSIST, the village HBC volunteer, and representatives from community groups such as income-generating, women's, agricultural, savings and loan, and PLHIV support groups. The community improvement team members were identified through a rapid baseline assessment that mapped out existing community groups in each community and helped determined which pre-existing community groups were meeting regularly and willing to participate in the community improvement team activities. ASSIST staff worked together with the Council Health Management Team (CHMT) and health facility staff to determine and train appropriate people to coach and support each community improvement team. In addition, the HBC volunteer in each of the five

villages was trained to be an internal coach, serving as the team leader at the community level and the information link between the community and facility.

Coaches and ASSIST staff oriented community team members to improvement, HIV/AIDS, key health messages, ethics, advocacy, and data. Health messages around HIV included transmission, need for testing, importance of attending the clinic and continuing antiretroviral therapy, HIV prevention, and disclosure. They also worked with the community members to understand and interpret data. Community groups recorded and reported data to the community improvement team on the number of people in the households they had reached, how many said would go for health services, and how many actually went. Once the community improvement teams were established and received buy-in from their respective groups, they began to meet monthly to review data to determine where there were gaps, conduct a simple analysis of what the situation was, and testing possible solutions to address the gaps. In this way, the team continuously collected and reviewed data to determine whether care for PLHIV was improving. The team was able to demonstrate increasing accessibility of health services to community members and provide more accurate and timely information exchange between health facilities and households.

Results

As a result of incorporating health talks in their regular meetings and developing messages for community group members to discuss at home, there was an increase in the number of people tested regularly for HIV and a significant increase in the proportion of men being tested. There was an increase in the number of referrals made by the HBC volunteers in addition to strengthening the process of tracking referrals. With the community system, the HBC volunteers received and sent information to households through community groups without having to visit each one individually. Over 7 months, out of 44 individuals ever lost to follow-up, 23 clients were brought back into care, 5 were determined to have relocated, 11 had died, and only 5 were still lost to follow-up as of September 2014. While there will continue to be a small stream of clients newly lost to follow-up in these communities, there is now an active system for tracking and bringing back clients to care as soon as possible, using HBC volunteers, PLHIV groups, and client-chosen treatment supporters in order to maintain confidentiality.

Conclusions and Recommendations

This pilot project demonstrated that applying quality improvement methods at the community level through the CHSS model increased rates of HIV testing and retention in care of PLHIV by extending the reach of community-based health workers and creating efficient information flows between facilities, HBC volunteers, and community groups. The approach leveraged existing community resources by engaging a range of actors (community-based organizations, religious groups, livelihood groups, and other informal networks) to address HIV care at the community level. In this experience, increasing the frequency of open discussion of HIV issues in multiple community venues also seems to have reduced stigma and may have helped with disclosure and therefore increased uptake of HIV testing.

The CHSS approach is a promising strategy for strengthening community linkages to improve retention in HIV care and merits wider application. At the same time, raising interest among community groups and catalyzing action to form a community improvement takes time. Based on the Muheza experience, USAID ASSIST recommends:

- Before starting the intervention, get buy-in from leadership at regional, district, ward and village levels to help them understand the model and the value it brings.
- Conduct a simple baseline assessment in the start-up phase to learn about the communities, their populations, organizations, values, and the HIV situation.
- Avoid introducing external incentives that cannot be sustained by the local health system; encourage participation based on the values and interests of the groups and community.

I. INTRODUCTION

A. Background

The USAID Applying Science to Strengthening and Improve Systems (ASSIST) Project supports the Ministry of Health and Social Welfare (MOHSW) in Tanzania to improve the quality of HIV/AIDS care through innovative approaches to maximize access to services and retention in care and achieve better client-level outcomes country-wide. Significant efforts have been made to improve services at facility level. Less focus has been on the community level, despite the fact that the community provides the ideal environment for sustainable improvement.

In early 2014, ASSIST, with support from the U.S President's Emergency Plan for AIDS Relief (PEPFAR) began the Community Linkages activity in five villages of Muheza District of Tanga Region in Tanzania, building on existing work to increase retention in the HIV continuum of care. In total, there are 135 villages in the 33 wards of Muheza District. These villages were chosen due to their location close to Muheza District Council given limited funds for travel. The five villages lie in the catchment areas of Mkuzi Health Center and Kilulu Dispensary, out of a total of four and eight villages, respectively, in their catchment areas. The dispensary reports and refers patients to the health center. The Community Linkages component aimed to improve care for people living with HIV (PLHIV) by increasing linkages between health facilities and communities.

The specific objectives of this activity were:

- To increase communication and linkages between health facilities and different types of community structures, including encouraging HIV testing
- To improve follow-up and referrals of PLHIV from the community to the health facilities and vice versa
- To decrease loss to follow-up of PLHIV by engaging community systems in supporting PLHIV with emphasis on retention of pre-anti-retroviral therapy (ART) and ART clients in care

In Muheza, ASSIST supported community groups to assume responsibility for and support the work of the home-based care (HBC) volunteers to improve access to HIV/AIDS care and retention to services in their villages using the Community Health System Strengthening (CHSS) model. The CHSS model engages informal and formal community groups, such as village government, PLHIV support groups, schools, religious groups, agricultural groups, and savings and credit groups, to add health issues into their business agenda and sent a representative to the community improvement team. The community health system leverages these existing community structures in a new way to support the efforts of community health workers, thereby reaching more homes more quickly with health messaging and linkages to facility-based services. While the CHSS model provides an external catalyst (in this case, ASSIST) to get the process started, tapping into existing structures and their intrinsic motivation to have a healthier community lays the basis for a sustainable system.

The CHSS model contributes to the PEPFAR 3.0 strategy by improving the performance of community-based health workers and increasing linkages between communities and health facilities to improve HIV prevention, treatment, and care, thus contributing to morbidity and mortality reduction. It also creates a sense of ownership of community sensitization activities by the community groups. This contributed to people-centered care as the communities themselves take on the responsibility and ownership for developing a system of working together to support PLHIV. .

B. Situational Analysis

Before ASSIST began supporting these sites, our situation analysis, conducted in November and December 2013, found that the government home-based care volunteers who lived in the villages were the major link between the facility and the community. The HBC volunteer's role was to visit PLHIV in their

homes, take care of their minor ailments, and refer the clients to the nearby health facility as necessary. HBC volunteers in Tanzania offer education on testing and treatment of HIV, support to people living with HIV, and share information about the community's health with the facility. The HBC volunteers would send information from the health facility to PLHIV and vice-versa. HBC volunteers were responsible for covering 20-25 households and reported that they often felt overwhelmed and that they could not reach every household with the information they were supposed to be providing. HBC volunteers worked only on a house-to-house basis, making it hard to reach large numbers of the community. HBC volunteers could not physically track all lost to follow-up patients due lack of transport and other logistical support.

Health facility staff interaction with the communities was limited to clinic visits, community campaigns such as immunization, and through the HBC volunteers. This resulted in low uptake of HIV services by PLHIV due to a lack of understanding of the benefits of care, an ineffective referral system, poor follow-up, and high rate of patient loss to follow-up. To get patients to come back to treatment, the health facility staff tried calling them on the phone, but this had not worked well.

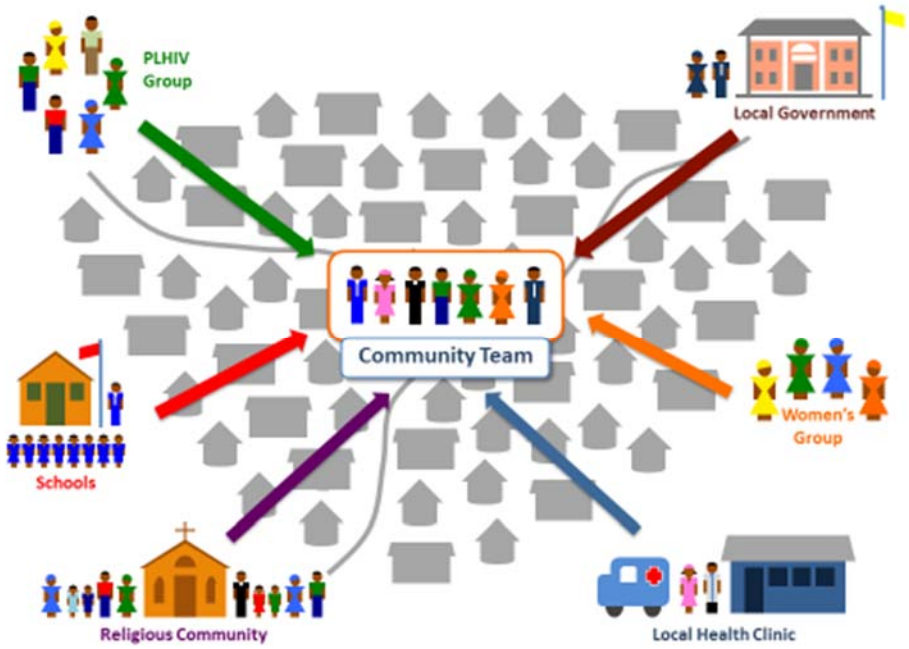
At the district level, there was an HBC Coordinator who supported the HBC volunteers and typically interacted with HBC volunteers at the facilities when receiving reports. In addition, all HIV clients identified a treatment supporter or assistant who may be a family member or friend whose role is to ensure the client takes medications, keeps appointments, and gets other support. HBC volunteers could also contact the treatment supporter of a client who was lost to follow-up. However, this system in and of itself was not bringing clients back. Furthermore, male participation in PLHIV support groups was limited, resulting in poor uptake of services as well as a lack of support for them, including peer treatment supporters.

II. INTERVENTION

A. Community Health System Strengthening Model

The CHSS model was thought to be a promising strategy in Muheza, where rural communities, though possessing limited material resources, have their own informal health and social welfare systems where community members make decisions and work together to improve the health of community members and the general welfare of the community. In the CHSS model (Figure 1), representatives from each community group, representatives from the facilities, and delegates from local government, all come together to serve as a community improvement team for the purposes of identifying local HIV and health gaps to meet local needs and to develop and test strategies to bridge those gaps. The community improvement team applies quality improvement principles to strengthen the performance of the community health system by identifying and strengthening the processes by which participating groups and structures functioned and interacted with each other to increase HIV testing and awareness in the communities and keep PLHIV in care. As a group, the community improvement team collects and reviews data to determine whether care for PLHIV is improving. When all elements of the CHSS model are harmonized, functioning well and coordinated with the efforts of HBC volunteers and other community-based care providers, health services became more accessible to community members and accurate information exchange between health facilities and households occurred more rapidly and effectively.

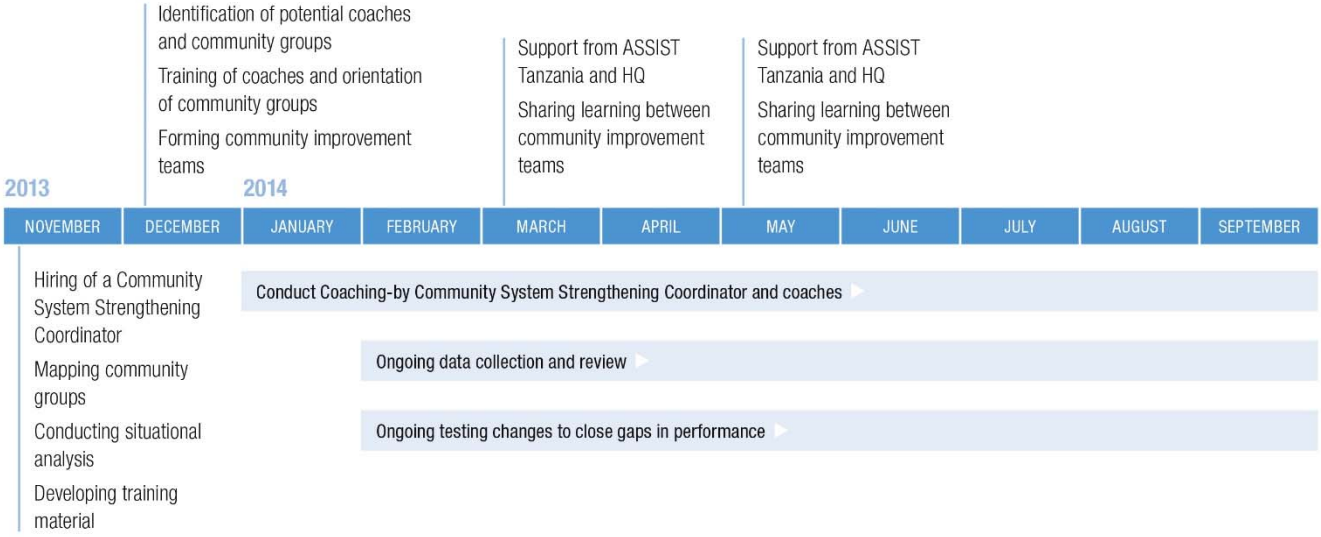
Figure 1. Community Health System Strengthening (CHSS) Model



B. Steps to Implement the CHSS Model

The USAID ASSIST Project began the intervention in November 2013. The main support for the process in Muheza was the hiring of a local Community System Strengthening Coordinator (CSSC) who, with support from technical advisors based in Dar es Salaam and the US, helped to establish and then met frequently with the community improvement teams to review the progress of their work, share health data from the community, and provide training to the community improvement teams. Figure 2 provides an overview timeline of the key technical support activities, which are described below.

Figure 2. Timeline of key activities



- **Determine appropriate coaches:** USAID ASSIST staff worked together with the Council Health Management Team (CHMT) and health facility staff to determine appropriate people to coach and support the community improvement teams. The coaches included the District HBC Coordinator, the focal person for HBC from the health center, the focal person for HBC from the dispensary, one District Social Welfare Officer, one Agricultural Extension Officer, and one Community Development Officer. In addition, one HBC volunteer from each of the five villages was trained to be an internal coach, serve as the community improvement team leader, and be the information link between the community and facility. All of these groups were supported by the ASSIST Community Systems Strengthening Coordinator who lived in the same district and interacted with teams on a weekly basis.

Participants from community groups demonstrating drawing line graphs on the ground using locally available materials during orientation of community groups in Muheza District. *Photo by Ram Shrestha, URC.*

- **Train coaches:** Once the group of coaches was identified, ASSIST staff and the District HBC Coordinator trained them on analyzing gaps in performance and on the ideal processes of access and retention to care and referrals for PLHIV in the community. ASSIST provided copies of the national HBC Standard Operating Procedures and stationery for use by the coaches.
- **Create community improvement teams:** The first step was for USAID ASSIST staff, working with community leaders, HBC volunteers, facility, and district representatives, to conduct a rapid baseline assessment that mapped out existing community groups in each of the five villages. Together they developed an inventory of community-based local organizations working in each of the villages, identified implementing partners working in those wards, and listed the services provided by each of these organizations for purposes of referring clients who have psycho-social support needs such as nutrition, income generation, social welfare, etc. In addition, as this community improvement work would not have external incentives, the group identified what the personal gains would be for the groups to be involved. For example, healthier people are better able to farm and produce income. Following the inventory, they determined which pre-existing community groups were meeting regularly and willing to participate in the community improvement team activities. Finally, they worked with groups to identify volunteers to participate in the community improvement teams. Multi-sectoral AIDS Committees (MACs) are supposed to be active at the district, ward, and village levels; however, the assessment revealed that these were not active at the ward and village levels. Therefore, the basis for developing the teams was the village government structure. A typical community improvement team was composed of a village government leader who had gone through the orientation course by ASSIST, village HBC volunteer, and representatives from community groups, such as income-generating groups, women's groups, agricultural groups, savings and loan groups, PLHIV support groups, etc. The number of team members varied according to the particular village but averaged between 10 and 12.
- **Orient community improvement team:** Coaches and ASSIST staff oriented community improvement team members on HIV/AIDS, key health messages, ethics, advocacy, and data. Health messages around HIV included transmission, need for testing, importance of attending the clinic and continuing antiretroviral therapy, HIV prevention, and disclosure. They also discussed

how to talk openly about HIV with others. They worked with the community members to understand data. By using simple, locally available materials like empty water bottles, notebooks, and pencils to draw line graphs on the floor, the community group members were able to demonstrate their understanding of tracking and plotting data. As part of the orientation, they discussed the roles and responsibilities of each type of community group. For example, teachers would discuss HIV issues in the course of teaching other subjects in class or among themselves. Finally, the coaches provided community group members with similar messages as above about HIV to communicate to their family members.

Community group members conducting their regular group meeting where they also discuss health issues. *Photo by Ram Shrestha, URC.*

- **Create data system:** Community group members recorded and reported at the village community improvement team meeting the number of people in the households they had reached, how many said would go for a health services, and how many actually went. This information was recorded in a notebook as part of the minutes of the team meeting and was shared with the facility. Each community improvement team was provided with a notebook by USAID ASSIST to record minutes of their meetings.
- **Embed health issues into the community group business agenda:** Following orientation, community improvement team members then returned to their respective groups and solicited acceptance and willingness to participate in improving HIV care for their communities. The community improvement team members discussed with their respective group what their personal gains were, such as saving lives and offering services to close relatives. They asked groups if they were willing to spare one hour and discuss health issues including HIV/AIDS during their regular meetings. They also provided some HIV/AIDS reading materials to each group.
- **Integrate HIV/AIDS health talks in regular community group meetings:** After groups agreed to include health discussions in their meetings, community improvement team members helped them create a standard meeting agenda that reflects HIVAIDS care in addition to their core business. Village leaders played a key part in helping them think about the existing and locally available opportunities and spaces to promote and access health services, such as community group meetings, household visits, drawing on important people in the community, school classrooms, tree shades, and primary court halls.
- **Hold regular meetings:** Once the community improvement teams were established and received buy-in from community groups, the improvement team began to meet monthly to review data from community groups and to determine where there were gaps in HIV care. They conducted a simple analysis of what the current situation was, tested possible solutions to address the gaps, and again reviewed data to determine if the gap was closed. The community improvement team also received information from the facility through the HBC volunteer on areas such as the general number of patients lost to follow-up without discussing specific patient information.

III. RESULTS

The community linkages activity engaged and brought together both the community-based and facility-based actors to create common understanding of how each actor's role was important towards linking of both pre-ART and ART clients to community- and facility-based services. Stakeholder engagement

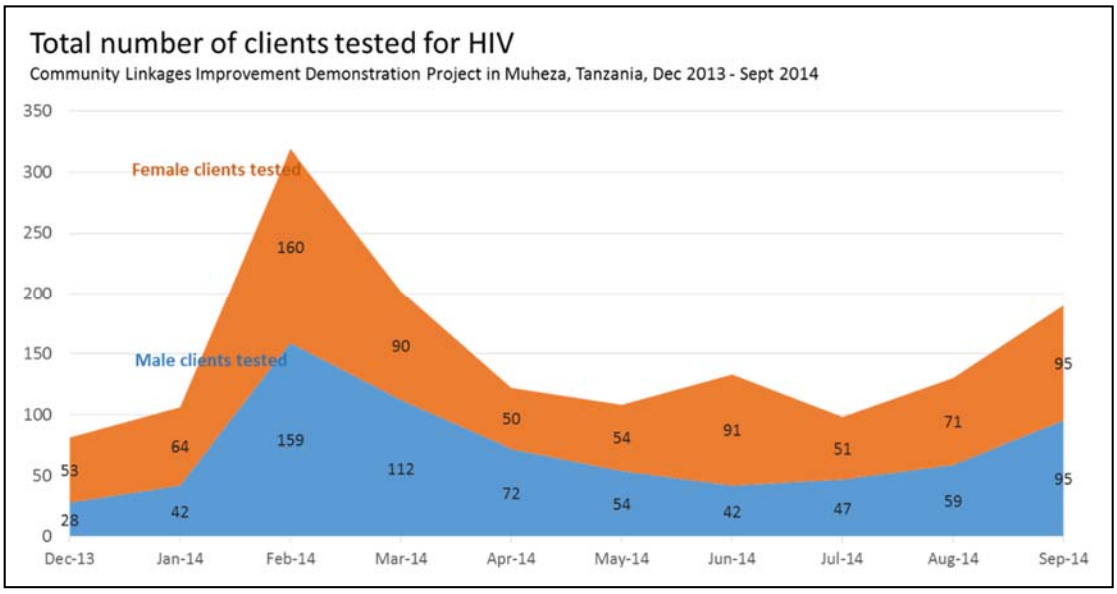
helped to ensure all stakeholders understand how working together was crucial to achieving set goals and what activities and outcomes they were responsible for.

Three main areas of results were seen from the work of the five community improvement teams: 1) better communication between the health facilities and the villages; 2) increased follow-up and referral of PLHIV; and 3) reduced loss to follow-up among PLHIV in the villages.

A. Increased Communication and Linkages between Health Facilities and Communities

- **Expanded the reach of home-based care providers**: The application of the CHSS model increased the reach of the home-based care providers and was an effective approach for reaching more households. The HBC volunteers working on their own had a hard time reaching all households. When community groups shared messages, they were able to have a larger reach in a short amount of time. Increasing the open discussion of HIV issues in multiple community venues seems to have reduced fear of discussion within the household and may have helped with disclosure.
- **Increased testing for HIV**: There was an increase in the number of people being regularly tested for HIV, and notably, an increase in the proportion of men seeking testing in all five villages. As shown in Figure 3, the initial spike in number of community members tested for HIV reflect a larger number of community members who were not previously tested being tested and includes the results of a specific outreach activity in Kwemsala Village in February 2014, which had a large turnout.
- **Meeting the increased demand for outreach HIV testing and counseling by the communities:** Some villages which were far from facilities requested outreach services to make HIV testing available in their communities. The community improvement team and facility staff established an outreach clinic day to cover the communities within their locations. The facility managed to develop a plan for staff and logistics to manage the process. Community groups mobilized community members and communicated the dates of outreach visits. The facility staff made testing services available and accessible for people who have been mobilized. Community group members encouraged uptake of services through intra household discussions.

Figure 3. HIV testing in five communities, Muheza District, Tanzania



B. Improved Follow-up and Referral of PLHIV between the Community and the Health Facility

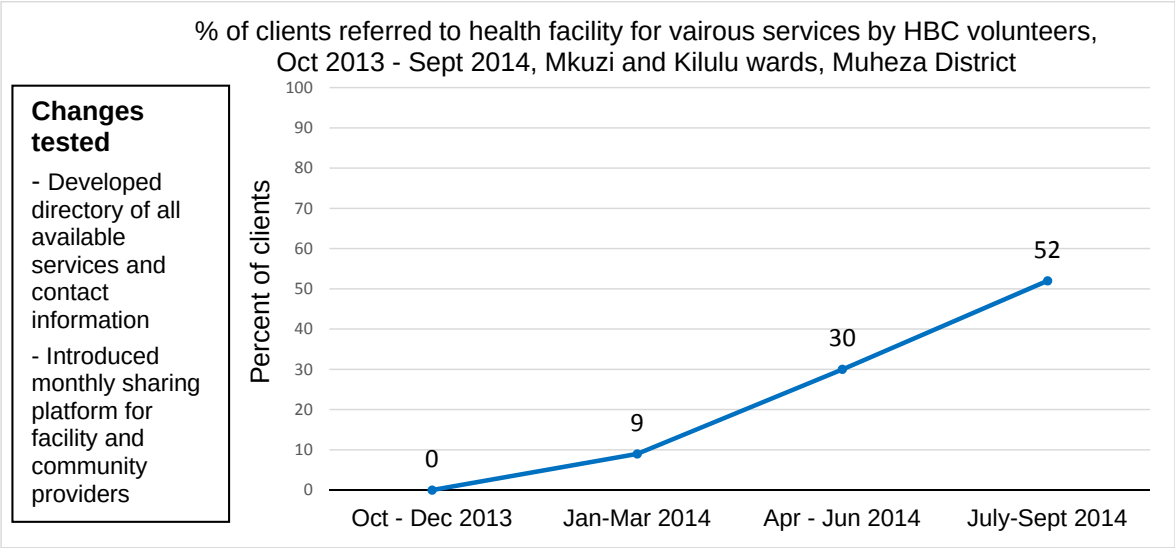
- **Identified barriers to referral and improved the referral system:** The community improvement teams conducted a situational analysis of the gaps within the existing community-facility referral system. The gaps that were found included failure to track clients who were referred to the particular services to see if they received the service and a lack of feedback from the point of service where the patient was referred to and sometimes failure to respect the referral from the HBC volunteer, especially in hospitals. As a result, the community improvement teams created a referral network of facility and community-based actors whereby the HBC volunteer tracked clients to and from the communities and facilities.
- **Developed a directory of services:** During the baseline, ASSIST staff together with the district, facility, and dispensary staff took an inventory of all of the organizations that existed and the services that they provided. They developed a directory of all available health, social, and economic strengthening services and respective providers' contact information and made it available to all the HBC volunteers. The directory could be used by anyone who came in contact with an HIV-positive community member in need of services. For example, one PLHIV support group provided funds for food and accommodation to an HIV-positive woman who had no money for food.
- **Built the capacity of PLHIV, PLHIV support groups, and health facility providers to effectively track, follow up, and link clients:** CHMT and ASSIST staff provided supervision and capacity building on referrals and health information. They trained facility staff, HBC volunteers, and community groups on referral and documentation. They were also trained on data collection, compilation and analysis related to referral data. The community groups were provided with health education on HIV and AIDS, while PLHIV groups were more involved in tracking patients.

  Improved functional linkage, referral, and follow-up mechanisms: All five community improvement teams were introduced to ideas to improve the referral networks. There was an existing government form for referrals that was not being utilized well by the HBC volunteers. They improved the process so that the client would take this form to the facility or other medical referral point and then would bring it back to the HBC volunteer after the service was provided. **Error! Not a valid bookmark self-reference.Error! Not a valid bookmark self-reference.** reflects improved referrals as a result of engagement of community groups. HBC volunteers began to track referrals, which had not previously been happening (October – December 2013 data). Together with the community improvement teams, the HBC volunteer began to track the number of clients referred to facilities for various services, depending on their needs.

C. Decreased Loss to Follow-up of PLHIV by Engaging the Community System

- **Use of treatment supporters by the HBC volunteer to trace clients:** While HBC volunteers were pre-existing, the community system and improvement approach helped them become more functional and connected throughout the community. The HBC volunteer and PLHIV groups obtained contact information and address of clients and treatment supporters (telephone number, village, and ward) from the health facility. The HBC volunteers paid home visits to households with lost clients and to those with special needs. PLHIV group members helped HBC volunteers trace those lost to follow-up (LTFU) and update clients' contact information. PLHIV from peer educator groups and PLHIV support groups helped trace their peers who were lost. Names and identifying details on those who were lost to follow-up was limited to the HBC volunteer and PLHIV to protect the privacy of community members with HIV.

Figure 4. Improved referrals through engagement of community groups



- **Enhanced communication between facilities and communities:** The HBC volunteer obtained information on those who were lost to follow-up, defined as missing the clinic appointment for three consecutive times or three consecutive months. The information provided to the HBC volunteer included names of LTFU patients, their treatment supporter, geographical location, telephone numbers, etc. The HBC volunteer and PLHIV groups used this information to track treatment supporters and patients who had fallen out of care. In March 2014, community improvement teams started tracing those clients who were lost to follow-up and brought patients back to ART. As shown in Figure 5, over a seven-month period, out of 44 individuals ever lost to follow-up, they were able to bring back 23 clients and determined that five had relocated and 11 had died. As of September 2014, there were only five of the 44 patients still lost to follow-up. While there will continue to be a small stream of clients newly lost to follow-up, there is now an active system for tracing and bringing back clients to care as soon as possible.

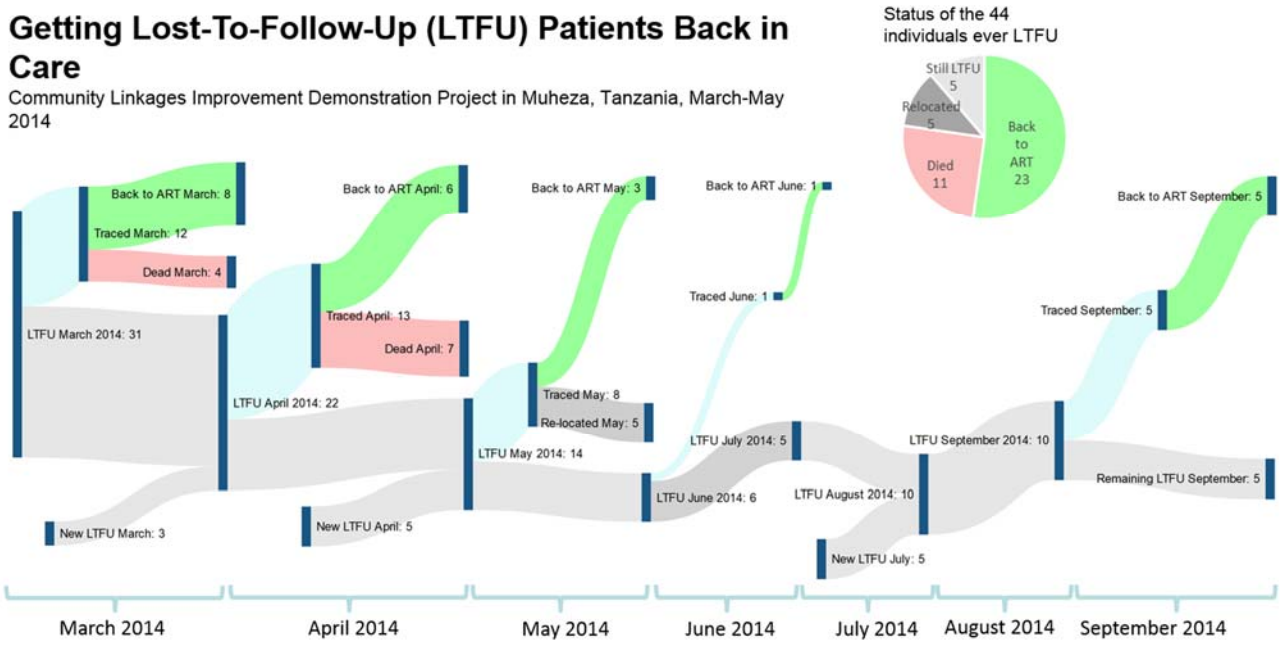
D. Current Status

USAID ASSIST support to these communities ended in September 2014. In February 2015, a phone survey of the villages was conducted to determine how the community improvement teams were continuing to function. All of the teams were continuing to meet twice a month, share reports from the community groups, and work with the HBC volunteer. Community groups continued to discuss health issues as part of their regular agenda, including the need for HIV testing, importance of initiation and continuation of treatment, and nutrition. In addition, each group's representative to the community improvement team continued to provide an update on the village data from the HBC volunteer.

Community improvement team members contacted reported seeing some changes in their communities, such as a more sensitized population about HIV, pregnant women more actively getting tested for HIV, and male partners accompanying pregnant women to antenatal care visits. The community groups continue to collect data and share it with facilities through the community improvement team and HBC volunteers. Community improvement teams are being supported by the two facilities, the District HBC Coordinator, and the community coaches, including an Agricultural Extension Officer.

The challenges that they reported include coaches (and therefore HBC volunteers and communities) have not received any updated knowledge about HIV/AIDS in almost a year. In addition, there is turnover in the community group representatives on the community improvement teams, which creates some confusion and requires continual orientation of new members.

Figure 5. Reduction of lost to follow-up in five communities, Muheza District, Tanzania



IV. DISCUSSION

A. Factors that Facilitated the Implementation of the CHSS Approach

- **Advocacy at all levels:** Before undertaking a community linkages intervention, it is important to advocate within the leadership at different levels, to help them understand the model and the value that it will bring to them. In Tanzania, the relevant leaders included the Regional Medical Officer, Regional Community-based Services Coordinator, District Social Welfare Officer, District Medical Officer, Ward Executive Officer, Village Executive Officer, and health facility staff. Engagement of these stakeholders from the outset created local government ownership for the intervention.
- **Initial assessment:** The baseline assessment at start-up was an important step to learn about the villages, their populations, community organizations, and the HIV situation. It was also the first opportunity to bring in district and facility level staff and have them work closely with community members on issues around HIV.
- **Presence of a dedicated Community System Strengthening Coordinator:** ASSIST found it was critical to have a staff member living and working close to the community within the district who could support the community improvement team in each village to get things up and running and then move on to the next village, making sure his visit coincided with the community group meetings. The coordinator also worked with facility managers to ensure that data flowed between the facilities and community groups. The coordinator worked closely and frequently with each of the five village improvement teams, helping them understanding the importance of the activity and the importance of bringing health issues into their respective group agendas and to their own households.
- **Coaching support:** The coaching team that was chosen worked well because ASSIST selected those who had already had responsibilities of supervision or administration of communities.

ASSIST trained them on issues around HIV/AIDS, introduced the CHSS model, and trained them on how to gather data to show results, using practical exercises.

- **Motivation:** There were multiple motivational aspects of the activity for community groups and members, including new knowledge and information on HIV and reviewing their own data. In addition, increased interaction with the HBC volunteers and health care workers appears to have been a motivating factor for the engagement of community groups. When convincing community groups to participate initially, time was spent to understand the values of each group and explain why having a healthy community and membership benefitted them in particular. These intrinsic, rather than external, motivations laid the foundation for sustainability. Even when visited unannounced, ASSIST staff observed that community groups continued to discuss health issues. It appears that they had internalized the problems and felt ownership in solving them, which also seemed to motivate them to continue and contributed to sustainability of the activity.

- **Role of the HBC volunteers in facilitating links between communities and facilities:** The HBC volunteer, who was a community volunteer who had been trained by the government or an implementing partner on home-based care, played a critical role in facilitating the community health system, serving as the vital link between the village and the health facility by participating in both community and facility improvement team meetings and visiting homes when necessary. Figure 6 outlines the various roles that the HBC volunteers played in the community linkages activity. Community improvement teams would receive information from various groups, such as numbers contacted at household levels or those who promised to go back, and the HBC volunteer would pass that information on to the facility. The facility would report how many people they received or who had come for testing, but only in general numbers with no names to maintain confidentiality. In this way, the community improvement team knew overall how well they were or were not doing in caring for PLHIV by comparing how many were reported by the community groups and how many actually went for services. These strengthened linkages between the existing structures in the community, the HBC volunteer, and the facility.

Figure 6. Roles of the home-based care volunteers in the Community Health System

- Trained as a coach for community improvement teams
- Oriented community group members to the CHSS model and improvement
- Assisted community groups in establishing community improvement teams
- Participated as member of the community improvement team
- Obtained information from other members of the community improvement team on sensitization activities of community groups and health gaps
- Provided updates to the community improvement team on data from the health facility and updates on health education topics
- Provided reading materials to community groups on HIV and AIDS
- Led the community improvement team in identifying topics in health to be discussed in individual groups (e.g., HIV & AIDS, ART, PMTCT, nutrition for PLHIV)

- **Shared learning:** Learning exchanges happened three times during the seven-month intervention, where 8-10 people from each village came together for some additional training on HIV messages and information exchange with representatives from the other community improvement teams. These exchanges were motivating to the groups and enabled them to share effective strategies and ideas with one another.

- **Analyzing data:** Coaches had better education than community group members so it was easy for them to understand the time series charts. The community groups were excited about the line graphs as they could be easily explained and they understood whether or not they were doing well. They were surprised that they could discover things from looking at the line graphs. They

could put the numbers and draw the line graphs on the graphs, but not necessarily on the piece of paper. Instead they were encouraged to make graphs using materials around them. Data collection and analysis was possible at the community level and allowed them to know their own progress.

B. Key Issues for Consideration in Applying the CHSS Model in Other Settings

- **Confidentiality:** It was critical that systems were set up that did not compromise the confidentiality rights of patients. When HIV testing or loss to follow-up data were discussed at meetings, they was discussed only in general terms of "this many were lost" and "this many were found" without using names. Names were only disclosed to those who were already known to the clients, such as the HBC volunteer, their own treatment supporter, and PLHIV peers. There is a potential for confidentiality to be broken if providers and communities are not well sensitized to the importance of this.
- **Intensity of start-up support:** Some intensive time with the community was necessary at the beginning to get the system set up, but that support was reduced as the community improvement teams started to function more independently. However, given the short timeframe of the activity, we do not have a good recommendation for the length of intensive work in order to ensure that the system is sustained.
- **Resources:** ASSIST did not pay anyone in the villages or health centers to participate in this work. The community groups should be informed right from the beginning that the intervention is meant to help the health of the communities themselves and that they should not expect any payment. The project did provide a staff member, the Community Systems Strengthening Coordinator and associated costs, such as a motorbike. The project also covered travel and meeting costs for community improvement team representatives to participate in the three learning exchanges.
- **Other limitations:** This activity was a pilot on a small budget, so the scale of the intervention was very limited—only five villages. There is a need to test the model at larger scale and for longer duration. The short time frame showed promising results but limits our understanding of the long-term needs for support. While there has been promising sustainability over the past four months, the long-term sustainability needs further research. There initially was a plan for control sites but we were not able to use them because of the short time, budget limitation, and cross-contamination from the project-supported sites.

V. APPLYING LEARNING TO NEW ACTIVITIES

The timeframe for the Community Linkages activity in Muheza was very short, running from March – September 2014. Nevertheless, it was evident that engagement of existing community groups significantly improved access to services, including HIV testing, and retention in HIV care. USAID Tanzania has asked ASSIST to apply the learning from the experience in Muheza to a new activity with CHMTs and implementing partners in Njombe, Iringa, and Shinyanga regions, to test the intervention with a larger population to strengthen community linkages for PLHIV. Some of the experiences and learning from Muheza will inform the design of the new activity in the following ways:

- ASSIST will develop a simple training guide for community groups for places that are distant to guide groups in organizing their own community system, holding meetings, and reviewing data.
- ASSIST will put one coordinator in each project-supported district. The coordinator will start by supporting communities around one or two facilities, and once they are up and running, move on to new communities.

- We will work with high-burden HIV/AIDS sites. At many of these sites, there are existing systems for HBC volunteers and PLHIV groups to track patients who fall out of the program and connect them with facilities. In order to implement the CHSS model on a larger scale, we will adapt and work with these existing systems. For example, the system using PLHIV groups is missing the component of getting messages into non-PLHIV households. We will use the CHSS model to improve communication and coordination between PLHIV groups, the HBC volunteer, and other community groups.
- One of the critical elements will be establishing a measurement system for communities and facilities to share and compare information to understand their performance and be able to act on that information to improve care.
- The ASSIST team will work with districts to see how they bring some neighboring villages together in small clusters to learn from one another in a more affordable way. Such shared learning is important for addressing issues when people move from one place to another.
- The geographic coverage is much larger for the new activity, creating the possibility of using a control area for comparison which can receive the intervention later.

VI. RECOMMENDATIONS FOR INCREASING COMMUNITY ENGAGEMENT IN HIV SERVICES

Based on the Muheza experience, we offer the following broader recommendations for other HIV programs seeking to increase community engagement in HIV services:

- Use or adapt the community health system strengthening model to improve aspects of HIV care, such as retention of patients. A critical component of this is the integration of an improvement approach which encourages communities to test out different changes to improve care and continually monitor data to determine their performance.
- Expand opportunities for more community groups to discuss HIV issues in multiple community venues. In this experience, increasing the frequency of open discussion of HIV issues in multiple venues seems to have reduced fear of discussion within the household and may help with disclosure.
- Before starting the intervention, get buy-in from leadership at regional, district, ward and village levels to help them understand the model and the value it brings.
- Conduct a simple baseline assessment in the start-up phase to learn about the communities, their populations, organizations, values, and the HIV situation.
- Identify an external change agent, whether project, district or facility staff, to help catalyze community groups, raise interest and assist in the formation of community improvement teams. While the concept is relatively straightforward, setting up the system can take time.
- Avoid introducing external incentives that cannot be sustained by the local health system: encouraging participation based on the values and interests of the groups and community will make the system more sustainable in the long run, even if it takes longer to get started.
- Address confidentiality issues early on to ensure that only those individuals that PLHIV have authorized are informed of their status.

USAID APPLYING SCIENCE TO STRENGTHEN AND IMPROVE SYSTEMS PROJECT

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