

# SUCCESS STORIES

From the Strengthening

Tuberculosis

and HIV&AIDS

Responses in East

Central Uganda

(STAR-EC) Project



This story book is made possible by the generous support of the American people through the President's Emergency Program for AIDS Relief (PEPFAR) and the U.S. Agency for International Development (USAID). The contents are the responsibility of JSI Research & Training Institute, Inc. (JSI) and do not reflect the views of PEPFAR, USAID, or the United States Government

## INTRODUCTION

**T**his book features the stories of people whose lives have been impacted by the STAR-EC project in East Central Uganda. Between 2009 and 2016, STAR-EC worked to increase access to and use of comprehensive HIV and tuberculosis (TB) prevention, testing, treatment, and care services throughout the region. The project worked at the district, facility, community, and individual levels to strengthen systems, improve service quality, and increase awareness of and demand for services.

East Central Uganda is home to 3.3 million people—roughly ten percent of the country's total population. Bordering Lake Victoria and bisected by the busy trade routes that run east-west from Kenya to Kampala, the region is characterized by people on the move. Bustling coastal and island communities see the daily comings and goings of the region's thousands of fishermen, and outposts along the highways are stopping places for truckers and traveling businesspeople who hail from places all over Uganda.

Addressing HIV among these dynamic communities posed unique challenges. While efforts to reduce the HIV burden throughout Uganda in the 2000s were moderately successful, by 2009 the decline in prevalence in the East Central Region stagnated at around 6.5 percent. The health system struggled to reach the region's highly-

mobile populations with the comprehensive services required to identify people with the virus and initiate and retain them in long-term care and treatment.

STAR-EC fostered coordination and collaboration at the community, facility, and district levels, working with civil society organizations, volunteers, health facilities, and district health offices to increase efficiency and coverage of essential HIV services, including HIV testing and counseling (HTC), antiretroviral therapy (ART), prevention of mother-to-child transmission (PMTCT), voluntary male medical circumcision (VMMC), tuberculosis (TB) screening and treatment, and behavioral prevention education.

Over more than seven years, the STAR-EC project and its partners have contributed to remarkable improvements in coverage and uptake of HIV and TB services throughout the region. Key project successes include:

- **A 44 percent increase in the percentage of adults who have been tested for HIV**
- **An increase in the number of HIV-positive clients enrolled in ART from 372 to 40,116**
- **An increase in the percentage of men who have voluntarily received medical circumcision from 37 to 57 percent**
- **An increase in the cure rate for TB cases from 30 to 74 percent**

These system-level achievements have improved the lives of thousands of real people throughout Uganda's East Central Region who have accessed life-saving medications and services. These are a few of their stories.







## HOPE FLOATS

In 2012, George, a fisherman living on Dolwe Island in Uganda's Nayamingo District, developed a terrible cough and pain deep in his chest. The pain got worse and worse until George was no longer able to fish. He went to the mainland to get cough medicines and various remedies, but nothing helped.

Finally, George split his savings of 300,000 Ugandan Shillings (approximately \$130.00), gave half to his wife to support their five children, and took the other half to pay for the 8-hour boat ride to the hospital in Jinja.

It was there that George tested positive for TB. Upon his diagnosis, he was told that he would need to stay at the hospital to recover his health and undergo eight months of treatment. Having just spent almost all his money to travel to Jinja, George could not afford to stay and be treated. Despondent, he returned to Dolwe. "I was without hope," he remembers. "I knew that I would die very soon from TB."

However, a few days after George returned to the island, a flurry of activity erupted in the village; a huge, steel fishing boat had anchored in the harbor and was unloading skiffs full of medical supplies.

The boat was the R.V. Hammerkop, a 50-foot fishing and research vessel hired by the USAID-funded STAR-EC project to carry tents, medication, supplies, medical personnel, and volunteers to Dolwe Island for a week-long integrated service outreach. STAR-EC set up tents offering HIV and TB prevention and treatment services, including TB screening by way of a mobile laboratory.

**"Now I get tested for HIV regularly, and take my wife with me to get tested, too. We will encourage our children to do the same and they will know better than I did about these diseases."**

George, weakened by the advancing TB, made his way to the tents on the first day, registered, and again tested positive for TB but negative for HIV. He was immediately enrolled in treatment, a daily regimen of antibiotics to which George would need to strictly adhere for eight full months.



*Stricken with TB, George had given up hope of survival until the STAR-EC project arrived on the shores of Dolwe offering treatment.*

George was assigned a village health team (VHT) worker—a local volunteer trained by STAR-EC to help link people in their communities to care and encourage patients to adhere to treatment. Michael, the VHT, went to George's house every day for all eight months of his treatment to check on George's wellbeing and make sure he was taking his medication.

"Michael came every day, no matter what," George recounts, gratefully. "It helped me remember to keep taking the medication, even after I started to feel better. He encouraged me to stay hopeful and told me that I was going to live."

George started feeling stronger a few weeks into treatment, and gradually started to fish again. He took his medication every day until the last day of treatment in December 2013. Upon completion, he was tested again and found to be TB-free.

George has learned a lot about TB and HIV prevention through his experience. "I also learned a lot about HIV through this experience—how people who have HIV are more likely to get TB. Now I get tested for HIV regularly, and take my wife with me to get tested, too. We will encourage our children to do the same and they will know better than I did about these diseases."

## LIVING PROOF



*Barbara is living with HIV on Dolwe Island and is alive and healthy thanks to the antiretroviral drugs made available to her through the support of the US-AID-funded STAR-EC project. Barbara was also trained by STAR-EC to mobilize members of her community to seek HIV and other health services.*

**B**arbara is well known in her community of Sigila, a village on Dolwe Island in Uganda. As a village health team (VHT) member, she has gained her neighbors' esteem by educating them about HIV and connecting them to health services. Barbara's warm demeanor and infectious laugh inspire confidence and trust.

Before today, however, Barbara was without hope, bed ridden, and facing death.

In 1997, Barbara was living on the mainland in a town called Wakiso with her husband and two children. She was pregnant with her third child when her husband fell gravely ill and died. "I was devastated and scared," she recalls. "I had no idea how I would support my family."

She and her children moved to her sister's in Kasubi, where Barbara struggled to make a living by selling foodstuffs. In 2003, Barbara started feeling sick. She was losing weight and became very weak. Her sister convinced her to go to the hospital, where Barbara tested positive for HIV and enrolled on antiretroviral therapy.

Barbara's health improved on treatment but she was barely making ends meet. After hearing that there were opportunities to make money

on Dolwe, Barbara moved to Sigila, a small town on the island, and found steady income selling food and other goods. However, she no longer had access to treatment because at the time ARVs were not available on the island. Too poor to afford regular trips to the mainland for ARVs, Barbara switched to a regimen of prophylactic Septrin, the only drug available on the island, and hoped for the best.

In 2011, however, Barbara's health took a turn for the worse. She became too weak to work and eventually could not get out of bed. "I was dying," she says. "Everyone who saw me in that condition—including my children—wrote me off as a dead woman."

Around that time, however, the USAID-funded STAR-EC project brought HIV treatment and prevention services to the island, and ARVs became available at the Sigila health center. STAR-EC also trained local VHTs to link people in the community to care, and Barbara was brought to the health center and resumed ARV therapy.

"I was so sick and at first the medication made me feel even worse," Barbara remembers. "But the VHT checked on me and encouraged me to stay on the drugs."

Barbara took the ARVs every day and returned to the health center each month to refill her prescription. She started regaining strength and, after a few months, felt healthy again. One day, she saw a flier at the health center calling for applications to become a VHT. Barbara applied, went through the VHT training program, and became a very effective mobilizer in her community. She was so good at communicating health information and linking people to care that STAR-EC designated her an expert client—a person living with HIV who is on treatment and trained to counsel and link others to care.

**"I was almost dead—I had no hope left. And now look at me! I am healthy and I can live."**

Barbara works at the health center and in the community six days a week. Although it is a big commitment, she is deeply gratified by the work. "I was almost dead—I had no hope left. And now look at me! I am healthy and I can live."

## CHOOSING PROTECTION

**M**asolya is a tiny island in Mayuge District, Uganda. The island, with 1,000 residents and almost no vegetation, is entirely supported by the income generated by the fishermen who come and go.

Peter is one of those fishermen. Peter and his wife live on Masolya, but he spends over half of the year on Lake Victoria, traveling between islands, mainland Uganda, and his hometown in Kenya. This lifestyle is typical of island fishermen, who are constantly on the move, chasing fish and selling them where they can. This population is identified as being at elevated risk for HIV transmission, since transience is often associated with risky sexual behavior and inconsistent access to health care.

The USAID-funded STAR-EC program, in collaboration with the Ministry of Health, promotes voluntary medical male circumcision (VMMC) to help reduce the transmission of HIV, particularly among most-at-risk populations, such as the fishermen who live on the islands. A one-time, minimally invasive surgical procedure, VMMC has been shown to reduce the risk of HIV transmission by 60 percent. STAR-EC has scaled up VMMC services throughout Uganda's East Central region. Every three months, the project packs a boat with tents, medical supplies, and medical personnel, and sails to the islands for a week-long integrated service outreach 'camp' to offer this high-risk population a range of HIV-prevention and treatment services, including VMMC.

In 2012, Peter went to a VMMC information session at one of the outreach camps. His wife had encouraged him to get circumcised, but he was wary of the pain and the amount of time it would take to heal. After talking with the health workers at the information session, Peter was reassured and decided to get the surgery.

"At first I was scared that it would hurt a lot and that the healing process would be uncomfortable," Peter remembers. "But the health workers explained everything told us would happen. They also said that the surgery would reduce our risk of getting HIV and help prevent other infections, as well. After talking with them, I decided that I definitely wanted to get the surgery."

Peter got circumcised that day and was surprised by how quick and painless the surgery was.

"There was no pain at all! I was up moving around shortly after the surgery. When my friends saw that I was not in pain, they also decided to get the procedure."



*After electing to get circumcised at a STAR-EC integrated service outreach in the Sigulu Islands, Peter uses his positive experience to encourage other men to get the surgery.*

In the years since Peter had his surgery, he has noticed that more and more men have also chosen VMMC, and that the practice has become a cultural norm. He attributes this in part to the STAR-EC-trained village health team (VHT) members—local volunteers who raise health awareness and link people in their communities to health services.

"In the past, fishermen were resistant to getting the procedure, but the VHTs have done much to educate people and now circumcision is common. As more and more men get the surgery, more people want it."

More men choosing VMMC means fewer new cases of HIV. Since the project launched in 2009, STAR-EC has increasingly scaled-up VMMC services in the region, resulting in more than 230,000 circumcisions in five years, a number which, statistically speaking, could prevent 12,000 new HIV infections. Of course, VMMC is only one part of reducing HIV transmission. As Peter noted, "We were taught during the counseling session that the circumcision would not give us full protection and that other measures, such as being faithful to our wives or partners, and always using a condom were still necessary to protect ourselves from HIV."



## ON AN ISLAND, ON TREATMENT



*Vincent receives ARVs each month from the BIWIHI health center, a nongovernmental organization supported by the STAR-EC project.*

**V**incent is a fisherman who lives on Dolwe Island, one of eleven habitable islands scattered off the southern shores of Lake Victoria in Uganda. Vincent moved to the island in 2012 from the mainland to fish on one of the many small commercial fishing boats that operate out of Dolwe's harbor. The life of a fisherman on Dolwe is unpredictable, sometimes demanding days or even weeks of travel throughout the lake and to various ports to catch and sell fish. The work is physically demanding and often dangerous.

Although Vincent is living with HIV, he is strong and healthy enough to endure these rigors because he takes an antiretroviral drug every day that allows his immune system to function normally. Vincent gets this life saving medication each month at no cost from the BIWIHI Health Center, located just a short walk from his home.

BIWIHI is a nongovernmental organization that receives financial and technical assistance from the USAID-funded STAR-EC project. Since 2010, STAR-EC has collaborated with BIWIHI and the Ministry of Health to provide the people of Dolwe with reliable HIV prevention and treatment services.

Vincent tested positive for HIV in 2004 and enrolled on ART in his home in Mayuge district. He knew that his life and health depended on taking his medication every day, but his highly mobile lifestyle made it difficult to do so. When Vincent decided to move to Dolwe for more regular work, he was unsure how he would get his medication. Luckily, when Vincent arrived on Dolwe, he found the BIWIHI office on the busy harbor beach and registered to receive ARVs each month from the health center. He also met with a STAR-EC trained village health team (VHT) member, a local volunteer enlisted to link community members to health services. The VHT continues to check in with Vincent to make sure he is feeling okay and that he has not had any trouble with his medication.

"Staying on treatment is much easier on Dolwe," Vincent explains. "I can walk to the health center to pick up my medication. The ARVs are always there when I go each month and visits from the VHT remind me to take my medication and reassure me that I can get help if something goes wrong."

Vincent's adherence to ART allows him to live a productive life and renders him far less likely to pass the virus to his wife, who does not have HIV.

"I am very grateful that these services exist on the island. I would be badly off without them."

**" Staying on treatment is much easier on Dolwe. I can walk to the health center to pick up my medication. The ARVs are always there when I go each month and visits from the VHT remind me to take my medication and reassure me that I can get help if something goes wrong."**



## EXTENDING ART SERVICES TO HARD-TO-REACH FISHING COMMUNITIES OF EAST CENTRAL UGANDA

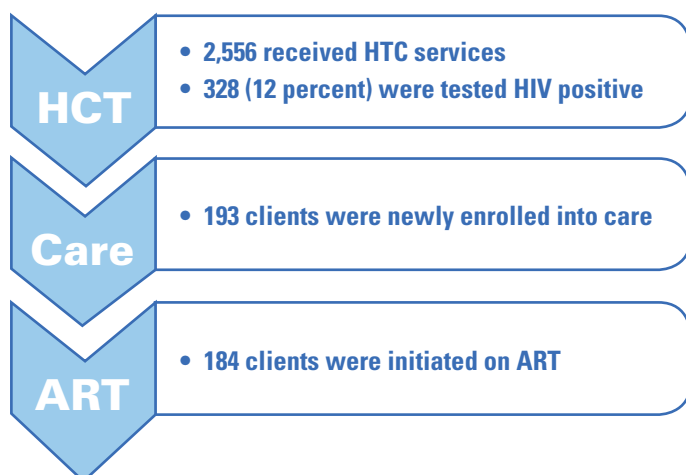
**T**he high concentration of most-at-risk populations (MARPs), especially fisher folk, is an important component of the HIV epidemic in the East Central region of Uganda. Many people in this community have multiple sexual partnerships and engage in other behaviors that increase their chances of contracting and transmitting HIV. Early uptake (as soon as a person tests positive for HIV) of antiretroviral therapy (ART) can interrupt the transmission cycle and reduce HIV prevalence.

The prevalence rate in east central Uganda, which fluctuated between 17 and 30 percent in 2011, is quite high. Thus, STAR-EC placed a special focus on increasing access and expanding coverage of HIV services to reduce new infections among fisher folk in the Sigulu and Sagitu islands.

Since 2011, STAR-EC has brought a team of district clinicians to offer ART services on the islands. The clinicians arrive every month and stay for one week at a time. Their efforts are supplemented by an additional team of STAR-EC staff and district clinicians, who arrive quarterly and deliver a combined package of HIV prevention care and treatment services.

"The Sigulu Islands significantly contribute to the HIV prevalence in east central Uganda. However over the past four years, STAR-EC's monthly and quarterly integrated outreaches on these islands have reduced HIV prevalence from 30 percent in 2010 to 6.8 percent in June 2014," says Dr. Rhona Barusya, an HIV specialist in charge of treatment services.

### In 2012:



*Fisher folk waiting to receive HIV services at a STAR-EC-supported ART camp.*

Village health teams on the islands have been trained to support clients on ART and the few health workers on the islands have been mentored so they can provide services when teams are not visiting. A total of 2,556 fisher folks were reached with HIV testing and counseling services during STAR-EC-supported integrated outreaches in 2012. Of these people, 328 (12.8 percent) tested HIV positive, 193 were newly enrolled into care, and 184 clients were found medically eligible to start on ART. With such interventions, there is no doubt that new diagnoses of HIV will be prevented and people living with HIV on the islands will have easy access to medical services.



*A STAR-EC-trained laboratory advisor takes a blood sample from a client on the Sigulu islands.*

## ACCESS TO ANTIRETROVIRAL DRUGS TRANSFORMS THE LIVES OF AN HIV POSITIVE COUPLE



*This HIV-positive couple (not Richard and Matilda) pictured at home with their children also rely on consistent access to antiretroviral drugs from their local health center.*

**M**atilda and Richard met while they were waiting in line for antiretroviral (ARV) drugs at a health clinic in Nayamingo, Uganda. Although such a place is not usually associated with romance, by virtue of where they met, the pair had already established what many never do: they knew their own and each other's HIV status. When they learned that they shared the status of being "single" as well, they bonded over their struggle and gradual acceptance of living with HIV, and became a couple.

Before Richard met Matilda, he was a fisherman living in the Sigulu Islands. When he got sick, his parents convinced him to come home to the main land so he could get medical care. Because he had become too weak to fish, Richard took his parent's advice. When he got home he visited a health center supported by the USAID-funded STAR-EC project. Richard tested positive for HIV, but a STAR-EC-trained health worker told him he could survive and live a healthy life as long as he started and stayed on HIV treatment. Richard began on a one-pill-per-day regimen, and within a few months of faithfully taking his medication, he began to feel like himself again.

Meeting and falling in love with Matilda was another positive side-effect of the treatment. "I never expected anything good to come of knowing my status, much less having HIV. But it led me to meeting and having two children with Matilda," says Richard.

Despite the fact that Richard and Matilda were in treatment, their first child was born with HIV because Matilda was not yet fully adherent to her medication regime. She is now, however, and the child is too. Both are healthy. By the time their second child was born, Matilda was taking her medications regularly and the baby was HIV-negative.

The health and well-being of Richard and Matilda's family relies on their access to the medication that manages HIV and keeps them from getting sick. The health center where the family retrieves its medication is consistently stocked with ARVs, thanks to the support of the STAR-EC project, which has built the capacity of health centers to deliver ARVs throughout the region. In five years of project implementation, STAR-EC increased the number of health centers that are accredited to distribute ARVs from 43 to 95.

"The health center has never turned us away because they lacked medication," says Matilda. "We go there every month and each time come away with our pills."

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**"The health center has never turned us away because they lacked medication. We go there every month and each time come away with our pills."**

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Richard's parents did not turn on their son—or his new wife—because of their status. They are proud grandparents who remind their son and his family of their medical appointments and to take their medication every day.

As Matilda says, "Richard's parents help us take care of ourselves, each other, and our children. Together we live with HIV."



## ACCURATE INFORMATION AND ATTENTIVE CARE ALLOW COUPLE TO HAVE HEALTHY CHILDREN

**J**ames and Rose have lived on Dolwe, the most populous of the Sigulu Islands, for 13 years. Although they had five children in 2011, they wanted more. After Rose was tested at a STAR-EC service delivery camp, she learned that she was HIV-positive. She knew that her husband had been unfaithful and was very distraught. However, she gathered courage, went home, and gave him the news. James was so upset and in denial that he didn't want to go for testing and counseling. Their hopes of having more children vanished because they were afraid that the children wouldn't live long. But after a STAR-EC trained village health team (VHT) member came and talked to him, James finally agreed to be tested. The results were positive and his CD4 count was low. The couple was put on treatment and taught about the implications of their HIV status and what they needed to do to live positively.

**“We still take our drugs. We are so grateful to the services brought by BIWIHI and STAR-EC. We are a much happier couple with all seven healthy children.”**

As Rose tells it, “In 2012, I conceived and my husband and I were scared as we had tried our best not to have any more children. We were sad because we didn't think our baby would live long. My husband brought me to the (STAR-EC-affiliated) Bukhooli Island Women's Integrated Health Initiative (BIWIHI) health center and we told the health worker of our predicament. She dismissed our fears and convinced us that we could have an HIV-negative baby. I was immediately enrolled in prevention of mother-to-child transmission (PMTCT) of HIV care. After a few weeks, the health worker informed me that I was expecting twins. My husband and I were shocked at the news but she assured us that all would be well as long as I took my drugs regularly.” BIWIHI is a USAID-funded civil society organization and STAR-EC sub-grantee that provides HIV services to all islands in the district. BIWIHI is in its second year of operation and offers services including HIV testing and counseling, PMTCT, antiretroviral therapy, and condom promotion and distribution.



*James and Rose with their twins, Kato and Babirye, who were born HIV negative, thanks to the staff at a STAR-EC-affiliated health clinic.*

James recounts, “My wife delivered the boy and girl normally. It was such a blessing because initially we had wanted two more children and now we decided that she will go for permanent family planning. When the twins, Kato and Babirye, were six weeks old, they tested negative for HIV. At six months, we returned to the health center and again they tested negative, as they did when they were tested again at one year and eight months. We were so happy and relieved when the doctor confirmed that our twins were healthy.”

“We still take our drugs,” says Rose. “We are so grateful to the services brought by BIWIHI and STAR-EC. We are a much happier couple with all seven healthy children.”

## BEYOND NEAT



*A well-managed record-keeping system allows patients, like this mother and her child, to receive services with less wait time. Here, a mother receives ART drugs from a health worker at a STAR-EC-affiliated clinic.*



*Improved ART records management allows health clinics and hospitals to effectively use their data, submit reports on time, and reduces the amount of time patients need to wait for services.*

With more than 1,200 clients in HIV care, Uganda's Kamuli Mission Hospital has the second-largest antiretroviral therapy (ART) clinic in Kamuli District. Despite the number of clients registered at the facility however, the hospital is managed by a team of three (a clinical officer, an HIV testing and counseling counselor, and a nurse). There is no one to manage ART client records, and before STAR-EC came in to set up a record-keeping system, things were a bit of a mess.

At that time, ART clients were responsible for their own treatment records, which they kept in exercise books that they were required to bring to every hospital visit.

Clients who could afford them kept their files in manila paper folders that cost about U.S. \$0.20. Unfortunately, records for the other clients were not protected. Boxes were the main mode of storage for all records (books and manila folders), which made it difficult for clients to access their records and increased waiting time for services.

The ART clinic staff could not even estimate how many clients the clinic was supporting. As the ART clinic in-charge James Isabirye recalls, "We couldn't account for our clients. We couldn't even tell how many got lost and how many were active. And submitting reports to the Ministry of Health and STAR-EC was a tremendous challenge." STAR-EC heeded the hospital's call for help by training the clinical team to use health management information system reporting tools to track client records, and explained the importance of timely and quality data for planning, decision making, and performance management.

After the training, STAR-EC gave the clinic registry books, primary data-capturing tools, and durable file folders for client cards. In addition, STAR-EC helped hospital staff install shelves in designated record rooms to facilitate filing and quick record retrieval.

STAR-EC also gave the hospital a computer and trained the site team to use an open medical records system to manage client records. "I am now a happy manager because I know how many clients our clinic supports. I can report defendable figures. We thank USAID for the funding, and MOH and STAR-EC for the partnership," smiles James.

The Ministry of Health is also pleased. Improved ART client records have resulted in the timely submission of high-quality reports and data. And, perhaps most important of all, the new record-keeping system has reduced the time that patients must wait before getting their life-extending treatment.



## STAR-EC LEADS A PATH FROM FEAR TO UNDERSTANDING

**T**hirty-three year old Margaret is one of many HIV-positive mothers who have benefited from STAR-EC's support in rural Uganda.

When Margaret's husband died in 2005 after a long illness, Margaret was alone with their two children. She, along with others in her community, believed that her husband had died of witchcraft. And when Margaret became ill two years later, she was convinced that the person who killed her husband had begun to follow her.

When a STAR-EC-trained village health team (VHT) member visited Margaret's home, he asked Margaret if she had ever been tested for HIV. She hadn't—and was afraid to be. But "The VHT told me it was good practice for one to know his or her HIV status, and referred me to the local health center for counseling and testing."

Margaret took his advice and, upon testing, learned that she was HIV-positive. The health worker gave Margaret some medicine and talked to her about positive living. "I felt comfortable there

and developed a good rapport with the health care workers," explains Margaret. "After two months on the medication my health improved. I stopped falling sick and started working normally. That is when I realized that my husband had not died from witchcraft."

During subsequent visits, Margaret learned that HIV-positive women can have HIV-negative babies if they attend antenatal appointments and follow health worker advice on how to prevent transmission of HIV to children. Margaret did both, and went on to have two more healthy children.

Today Margaret is healthy and supports her family by farming and her small business. She hopes to expand her farm's production so that she can put her children through school. She also lends her support to other women in her village who are coping with HIV.

"STAR-EC has helped me understand that being HIV-positive doesn't mean you can't care and provide for your children and yourself."



*A STAR-EC-trained village health team member (VHT) poses with two HIV positive mothers. VHTs play an important role in extending HIV services to the community and helping people living with HIV, like these two mothers, live healthy and productive lives.*

## USING COMMUNITY DATA FOR EVIDENCE-BASED PLANNING



*Kaliro district employees create a district action plan based on data disseminated from a recent LQAS. LQAS data will allow this district to better target HIV services to the people who need them.*

**W**hen STAR-EC began operating in East Central Uganda, it introduced the lot quality assurance sampling (LQAS) methodology as a cost-effective and time-saving monitoring and evaluation tool. LQAS is useful for determining how well health services are being delivered to communities and how well communities were using those services. The LQAS survey, which is conducted annually and covers all nine districts supported by the program, involves segmenting districts into five supervision areas. Data is gathered from individuals from randomly sampled households in each of the supervision areas.

The LQAS methodology is now considered the main data source for indicators in Uganda's 2011-2015 national HIV and AIDS monitoring and evaluation plan. Indicators measuring community-level social services, especially, are derived from the LQAS approach.

Francis Kyagulaga, the senior health inspector in Namutumba district, says, "Five years ago, we planned without data. Now our plans are

based on concrete data." Paul Mukooli, the community development officer in Mayuge District, concurs. "Before, we had no proper targeting because there wasn't any community-level data to guide our planning. But now with LQAS data, we can properly target services to beneficiaries."

To ensure accuracy, key district personnel are involved in planning for the survey, field data collection, tabulation, and dissemination of results at district, health sub-district, and sub-county levels.

Before the introduction of the LQAS methodology in East Central Uganda, districts had limited community and local data sources, so planning was not based on actual community need. Today, critical decisions and changes are based on the LQAS results.

For example, between 2010 and 2013, the Namutumba district health office prioritized Ivukula and Bulange sub-counties for HIV programs because the two sub-counties had performed poorly according to the HIV indicators. Surveys conducted later showed improved performance in HIV testing and counseling in Bulange and Ivukula sub-counties, from 49 percent and 46 percent in 2010, to 67 percent and 65 percent in 2013 respectively.

Due to its suitable features across different districts, LQAS has been used to develop a five-year district development plan, a district HIV and AIDS strategic plan, and a district management improvement plan (DMIP) by facilitating a situation analysis, trend tracking, problem identification, priority setting, resource allocation, and development of goals, objectives, and targets. If used continuously and satisfactorily, LQAS will keep contributing to the development of various districts and the nation.

**Surveys conducted later showed improved performance in HIV testing and counseling in Bulange and Ivukula sub-counties, from 49% and 46% in 2010, to 67% and 65% in 2013 respectively.**



## NUTRITION THERAPY SAVES LIVES

**N**orah used to be a cashier and sales woman with a prominent company in Uganda. In 2006, she was laid off because of frequent and prolonged illnesses. With no job and no recourse, Norah returned to her village to care for her children but, as her illness persisted, sought treatment at Jinja Hospital. Norah was tested, found to be HIV positive, and enrolled into chronic HIV care at The AIDS Support Organization (TASO) Clinic.

Although Norah was put on medication to prevent opportunistic infections and received other support care, her condition did not improve. By July of 2011, Norah had symptoms of HIV wasting syndrome, which include severe weight loss and protruding bones and muscle. Her skin was dry and she was unable to move without help. Norah lost hope of recovering and asked to be transferred to Kamuli General Hospital so she could die closer to home. Upon admission, Norah weighed only 33 kilos (74 pounds) and had a dangerously low CD4 cell count of 200.

Having been diagnosed with stage four AIDS and TB co-infection, Norah began TB treatment in August 2011 and began antiretroviral therapy (ART) shortly thereafter. Although she improved slightly, her weight failed to pick up despite the fact that she took her medications as directed. Her mid-upper arm circumference was only 16.7 cm, which indicates severe acute malnutrition.



*A STAR-EC-trained health worker conducts a nutritional assessment of a person living with HIV in the east central region of Uganda.*

**“I almost died of malnutrition. I am very grateful to my nurse, Joweriah, who sincerely counseled and encouraged me to eat all the RUTF. Now I am strong and can perform my normal household chores.”**

Norah needed nutrition intervention fast. Joweriah, a nurse, prescribed ready-to-use therapeutic food (RUTF) and dispensed a few sachets for an appetite test. Norah returned complaining that the RUTF was too sweet for her liking and therefore she had not been consuming the required daily eight sachets. Joweriah visited Norah at home twice to talk to her about nutrition and convinced Norah to give RUTF another try. One week later, Norah returned to the clinic and said she had been consuming the therapeutic food as prescribed and felt much stronger.

Nora is one of 48 people living with HIV in East-Central Uganda who have benefited from STAR-EC's nutrition intervention. Today, Norah weighs 44 kilos, her upper arm circumference has increased to 18 cm, and her CD4 count is 500. Norah no longer needs the nutrition care program, but her gratitude remains. “I almost died of malnutrition. I am very grateful to my nurse, Joweriah, who sincerely counseled and encouraged me to eat all the RUTF. Now I am strong and can perform my normal household chores,” smiles Norah.

## HELPING COMMERCIAL SEX WORKERS PRACTICE SAFER SEX



*Maria, a STAR-EC trained 'mentor buddy,' helps educate other female sex workers living on Masolya Island about HIV prevention strategies and connect them to health care.*

**W**hen Maria's produce stand was destroyed in a fire at the Kalerwe market in Kampala in 2013, she moved to Masolya Island. With no way to support her four children, she turned to commercial sex work.

Masolya is one of six habitable islands in Uganda's Mayuge District. Known as the 'red island' because of the unique color of its soil, Masolya has one run-down health center for its population of 1,638. Since May 2011, STAR-EC has been bringing clinicians to this island every month to offer HIV prevention and care services to the hard-to-reach residents, most of whom are fisher folk and sex workers. Part of STAR-EC's strategy is to recruit clients as community mentors for outreach. These trusted "insiders" are often able to persuade fearful or reluctant friends and neighbors to come to the STAR-EC camps for testing and care.

When Maria agreed to become a mentor buddy, STAR-EC taught her basic facts about HIV, including the correct use of condoms for prevention. She also learned about the importance of HIV testing and the relationship between sexually transmitted infections (STIs) and HIV.

**"I am very firm and insist on use of condoms because I value my life. And I always encourage my peers to use condoms and to find out their HIV status."**

"Currently, there are about eight commercial sex workers (CSWs) on the island. However, there is a lot of [CSW] movement between islands and new faces keep coming in. I have offered information to my peers and encourage them to use condoms to prevent HIV transmission," says Maria, who always carries a supply of male and female condoms and HIV-prevention brochures.

"One time when I was with a client, the condom broke. But this didn't alarm me so much because I had learned about post-exposure prophylaxis (PEP). I rushed to see a doctor who immediately put me on antiretroviral (ARV) medication for a month.

"But sometimes these clients are very stubborn and don't want to use condoms, they even offer to pay a higher fee," says Maria, who goes for HIV testing and counseling every three months and remains HIV-negative. "However, I am very firm and insist on use of condoms because I value my life. And I always encourage my peers to use condoms and to find out their HIV status."



*STAR-EC service delivery tents pitched in Masolya's famous red soil.*



## A SCHOOL CLUB SUPPORTS GOOD HEALTH

It is a cool Wednesday afternoon at St. John Bosco Secondary School in Uganda's Kamuli District. Nine young men from a 19-member school club are seated at school desks under a tree.

In attendance is George Luyiir, a teacher and voluntary male medical circumcision (VMMC) surgeon at Kamuli District Hospital. Paul Tinka, the teacher and club leader, opens the discussion. This is the first post-circumcision club in the East Central region of Uganda.

The club, which supports newly circumcised young men and encourages others to undergo the procedure, promotes health and prevention practices such as life skills development, abstinence, delay of sexual debut, and sexual negotiation skills. Members of the club discuss VMMC experiences, develop their knowledge of sexual health, and help to dispel the many myths and concerns about VMMC.

Coupled with personal support and access to George, the VMMC surgeon, the club mobilizes youth for SMC and supports them after they are circumcised. The club helps them adhere to proper post-VMMC care while reinforcing abstinence from sexual activity for the recommended six weeks following surgery.

"I was the first to go for the service," says Paul, "then when my fellow teachers, as well as students saw me back at school on Monday, many of them considered and started going to Kamuli Hospital for circumcision."

All members of the club received VMMC and found mentors and friends in both Paul and George. The youth say that an informational visit at which George explained the benefits of VMMC convinced many of them to go for the procedure.

"I was influenced by George and these guys' positive experiences with SMC," says the newest member of the group as he pointed at his peers in the support group.

Some of the boys, however, had never seen or been to an operating theater and were afraid of the facility as they thought it was only for the severely injured or ill people.

"I went with Mr. Tinka to the hospital for his day after surgery check up. When we saw George, Mr. Tinka introduced me as his student who also wanted to get circumcised. It was Mr. Tinka who encouraged me to overcome the fear," said Joseph, one of the club members.

With Paul's support, the club hopes to enroll female students and more newly circumcised males who will advocate for VMMC and provide sexual health education and guidance to the students at St. John Bosco and in nearby communities. Post-VMMC clubs, especially among youth, provide support following this simple medical procedure and the opportunity to learn and practice safer sexual health behaviors. And who better to learn from than trusted peers and teachers?



**"I was the first to go for the service," says Paul, "then when my fellow teachers, as well as students saw me back at school on Monday, many of them considered and started going to Kamuli Hospital for circumcision."**

## ANTIRETROVIRAL THERAPY TURNS A YOUNG MAN'S LIFE AROUND



*Young positives, like Kasadah Fahadi, attend an ART adherence support group for people living with HIV at the STAR-EC-affiliated Kamuli General Hospital.*

**Y**oung, HIV positive, and sightless, Kasadah Fahadi thought his life was over. But thanks to a peer support group in Namutumba, Uganda, Fahadi, now 22 years old, can smile.

Fahadi, whose parents and only brother died of HIV-related illnesses in the early 2000s, says that although he has been visually impaired since birth, he was relatively healthy until 2009 when he started falling sick time and again.

"My uncle, who works at Kakira Hospital in Jinja, came to the village and took me for a medical check-up. Several tests were done and I was given some medication. However, my uncle did not tell me the results of the tests or the reason I had to take regular medication, because he did not want me to be afraid," Fahadi explained.

But Fahadi's uncle could only protect his 17-year-old nephew for so long. After nine months Fahadi was referred to the antiretroviral therapy (ART) clinic, where he discovered that he was HIV positive and that his parents and sibling had died of AIDS.

"I was so terrified of death especially because I was also blind. How was I to survive?" Fahadi wondered. "My relatives have their own children and cannot provide for my needs."

Fahadi started taking antiretroviral (ARV) medication and returned to his village in Namutumba, where his life as an adolescent was difficult.

"I was afraid to talk with girls or approach anyone because I am blind and I feared they would discover that I am HIV-positive. I dropped out of school. I had to beg. I became socially isolated," said Fahadi.

Fahadi's luck turned, however, when a support group for people living with HIV (PLWH) in Namutumba recruited him to work and help other young PLWH in the community. Once he realized that other young people had similar concerns and experiences, he became less afraid and more confident about his future. Today, Fahadi is socially active and has refocused his life. This, along with taking ARVs, allows him to live happily and healthily.



# ABANDONING SEX TRADE TO START A DIFFERENT BUSINESS

**W**alking through the narrow streets of Iganga, one of eastern Uganda's busy town centers, Gloria warmly greets almost everyone she passes by name. She is well-known and clearly well-liked in this community, where she has made a name for herself as a talented hairdresser—a skill that has birthed a grand ambition.

**“Very soon,” Gloria explains, “I will have my own hair salon here in Iganga.”**

Joyful tears fill her eyes as she speaks; owning her own business is a dream that at one time seemed hopelessly out of reach. Opportunities for economic viability are scarce in Iganga, particularly for women. Gloria married at a young age to a man who physically abused her. She was desperate to leave and feared for her life, but didn't know where to go if she left him, or how she would support herself. A friend in whom she confided was a commercial sex worker—one of the many who worked along the busy highway that runs east-west through Iganga. Gloria saw that her friend was supporting herself without a husband, and saw a way out of her unbearable situation. Life as a commercial sex worker is dangerous—every transaction carries risks of violence and transmission of HIV and other STIs. Gloria remembers being scared all the time when she was a commercial sex worker—scared that she would be hurt and scared that she might contract HIV.

During that time, Gloria was often approached by village health team (VHTs) members—local volunteers trained by the STAR-EC program to raise awareness in their communities about HIV prevention and treatment options and link people to services. The VHTs encouraged Gloria to get tested regularly for HIV and to protect herself by using condoms. The VHTs also noted Gloria's gregarious, outgoing nature and asked that she become a peer educator, or mentor buddy, to teach other commercial sex workers about HIV and STI prevention and help connect them to services.

After training, Gloria became a mentor buddy, recruiting women to attend discussion groups at which she promoted the importance of condom use and encouraged her peers to take advantage of available HIV testing and treatment services.

“I loved talking to the women and teaching them how to prevent HIV and stay healthy,” Gloria recounts. She was highly engaged in the work, and proved to be a wonderful peer educator; other women trusted and sought her advice and information about their health. Though she was still supporting herself as a commercial sex worker, she took pride in her association with the VHT network of visible and respected community members.

Through her work as a mentor buddy, Gloria got connected to a charitable organization that paid for her to train as a hair dresser. She seized the opportunity, working at first as an apprentice, then spending over a year working at a salon, saving money to start her own business.

Gloria will, undoubtedly, face all of the challenges of business ownership with the same resilience that got her through the many hard times she has endured. When asked if she is happy in her new life, she laughs, gestures toward her smiling face, and says, “Just look at me!”



*Gloria is no longer a commercial sex worker, but continues to educate members of her community about HIV.*

## ACQUISITION OF TESTING TECH IMPROVES HEALTH CARE IN BUSOGA REGION

**T**he mid-mornings of two consecutive Wednesdays in September 2010 were historical for Iganga Hospital. Spirits were high among patients as well as health workers present at the outpatient department as word went round that high-tech machines were to be installed at Iganga Hospital Laboratory for the first time,” recounts Kakaire Kirunda, the Iganga District Laboratory focal person and head of Iganga Hospital Laboratory, with glee.

Kakaire notes that patients were excited when a CD4 machine and clinical chemistry analyzer were installed at Iganga General Hospital because they could now access CD4 testing at the hospital instead of traveling long distances to access the service in Jinja or Kampala. According to Kirunda, acquisition of this equipment changed the delivery of the testing service not only in the district but in the entire region.

“It was a big step toward improving the quality of health care in the region. Nobody would have ever imagined that such high-tech machines would be available at our facilities. The support from STAR-EC enables easy access to essential laboratory tests for both ART and general patient clinical care. In addition, turnaround times for laboratory diagnostic investigations significantly reduced,” explains Kirunda.

According to the hospital administrators, the beneficiaries of CD4 services have not only been from Iganga but also from the neighboring districts of Namutumba, Luuka, Kaliro, Mayuge, and Jinja.

Between 2010 and March 2015, the three laboratories supported by the STAR-EC program with funding from USAID performed more than 130,000 CD4 tests with more than 40,000 PLHIV.



*A Laboratory Technician operates a CD4 machine donated by STAR-EC*



## MENTOR MOTHERS SAVE LIVES AND FAMILIES



*When Namulondo stopped showing up for appointments at the Bumanya health center, two Mentor Mothers followed up with her at her home to convince her and her husband of the importance of adhering to ART to prevent passing the virus to her daughter.*

**S**TAR-EC implemented the mentor mother program to improve client retention and reduce loss-to follow-up in the prevention of mother-to-child transmission (PMTCT) of HIV.

Mentor Mothers have since been working with health workers, community support agents, and village health teams (VHTs) to track mother-baby pairs who missed their key appointments and help them to return to care. The outcomes have been impressive.

Namulondo is just one of the 363 clients who were lost to follow up then found and linked to care by Mentor Mothers. Namulondo had initially tested positive for HIV during her first antenatal (ANC) visit to Bumanya HC IV. With encouragement from two Mentor Mothers, she continued to attend ANC until she delivered her baby girl at the health facility. Namulondo returned to the clinic to have her daughter tested for HIV but never returned to get the results. When one of the mentor mothers who had worked with Namulondo during her pregnancy came calling, Namulondo's husband said that his wife was not home. When the Mentor Mother finally found her, Namulondo

told her that, "This husband of mine refused to let me go back to the health facility and threatened to beat me if I dared. He does not even want to hear the word HIV in this home."

The Mentor Mother counseled the couple on the dangers of domestic violence, told them about other couples who had similar situations, and explained the importance of PMTCT services. The couple finally agreed that Namulondo and her daughter could return to the health facility. There, the baby was re-tested for HIV and this time the couple returned for the results: the baby was HIV-negative. Namulondo's husband agreed to be tested too. He was positive, and enrolled in care.

Namulondo kept her promise to remain in care and is a vibrant member of the PMTCT family support group at the health center, where she also gets cotrimoxazole refills, family planning, and other clinical and preventive services. Namulondo is grateful to the program and people who have helped her family. "Long live the Mentor Mothers; you have saved my husband, my baby, and me!"

## A TRADITIONAL HEALER EMBRACES MODERN TB-TREATMENT

**M**aganda Robert, the 32-year-old head of the traditional healers' group in Namungalwe Sub-county, treats clients who have a variety of ailments.

However, after attending a STAR-EC training on TB intensified case finding and referral for suspected cases, Robert no longer conducts his business the way he used to. Instead of treating people who he suspects have TB at his shrine, he refers them to health centers. The training that Robert attended taught participants from Mayuge, Namayingo, and Iganga, the districts with the highest number of notified TB cases in East-Central Uganda, to recognize signs and symptoms of TB. The goal of the community-specific campaign, which trained 500 traditional healers, was to improve TB case detection and treatment rates.



*Robert, a traditional healer, visits a the household of a TB patient to help convince him to take his medication. A STAR-EC-trained linkage facilitator accompanies to help train Robert how to counsel patients.*

**"I don't let patients who I suspect have TB enter my shrine anymore. I instead refer them to the hospital immediately because I fear getting infected with the disease."**

During the course of the three-day training, health care providers and healers visited slum settlements, landing sites, and high-prevalence sub-counties with teams of 'linkage facilitators,' including local council leaders and village health team members from the respective communities. Simultaneous campaign efforts included radio announcements conveying information about TB and services, and a truck with a public address system that drove through communities to let people know about sputum outreach sites.

The training was clearly effective. When Kitawo Isaac and Nakisuyi Margaret, 70-year-old residents of Namungalwe, came to Robert's shrine seeking treatment, he knew what to look for. "I noticed that both of them were coughing a lot and had lost weight. On further inquiry, I found out that Margaret had abandoned her ARV regime." Despite her deteriorating health and Robert's urging, Margaret was unwilling to go back to the health facility where she had been getting treatment. So Robert did something he would not have prior to the STAR-EC training: he contacted a counselor at Namungalwe HC III, who convinced Margaret to get tested for TB and attend adherence sessions.

Unlike Margaret, Isaac took the traditional healer's advice and went to Namungalwe HC III, where he was diagnosed with TB and started on treatment. Robert, meanwhile, is thankful for his new knowledge.



# STAR-EC

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