Participant Experiences from One Community Program in Malawi

Malawi is making substantial progress in achieving UNAIDS 90-90-90 targets: 73 percent of adults living with HIV are aware of their HIV-positive status, 90 percent of those report being on antiretroviral therapy (ART) and 91 percent of ART users are virally suppressed. Malawi’s government and development partners continue to implement programs and interventions aimed at mitigating the impact of HIV on the population, and supporting initiatives to assist individuals in reducing risks to HIV exposure and increasing access and use of HIV services.

USAID/Malawi is supporting the five-year One Community (One-C) program (2015–2020), implemented by the Johns Hopkins University Center for Communications Program (JHU-CCP), with Plan International and Project HOPE. The overall aim of the One-C program is to support the Government of Malawi’s efforts to reduce new infections and mitigate the impact of HIV, ultimately improving the quality of life for Malawians. One-C implements programs and activities to increase utilization of HIV prevention, care, and treatment services, improve linkages to services at the community level, and foster the adoption of HIV risk reduction behaviors among three priority populations. The priority populations are: 1) orphans and other vulnerable children (OVC) and their caregivers, 2) out-of-school adolescent girls and young women (AGYW), and 3) other adult vulnerable populations (OVPs), including fishermen, estate workers, and market vendors. Elements of the One-C program also address the needs of people living with HIV (PLHIV), including adolescents and children.

Under Project SOAR, the Population Council in collaboration with the University of Malawi College of Medicine conducted quantitative and qualitative research in five districts (Blantyre, Chikwawa, etc.).

KEY FINDINGS

- All populations faced the daily challenge of meeting basic needs due to inability to find stable work. Engagement in One-C’s village, savings and loans program allowed participants to save and meet some needs but provided insufficient resources to change their realities.
- All populations credited the One-C program for their increased knowledge and awareness of HIV prevention and risk reduction strategies, and more positive attitudes toward HIV testing and services.
- Out-of-school AGYW who participated in One-C program expressed having greater self-efficacy about their sexual and reproductive health (SRH), sharing information with their sexual partners, and encouraging their partners to test for HIV. Few (8/35) reported not using condoms and more (18/35) noted use of family planning (FP) methods.
- Caregivers of OVC cited improved emotional and social well-being due to participation in One-C program, including improved relationships with family members and alleviation of stress.
- HIV-related stigma and discrimination as well as myths and misinformation remain significant barriers to HIV care and treatment among PLHIV, especially among AGYWHLV. Participants perceived some reduction in stigma in the community due to One-C sensitization and education.
- Food insecurity and poor quality of care at health facilities were key barriers to HIV care and treatment among PLHIV.
- Home and community-based services, referral and follow-up systems, and support groups for PLHIV were important strategies used by One-C to improve access to and use of HIV prevention, care, and treatment services.
The One-C Intervention

One-C leverages trained CRPs to conduct comprehensive home-based case management, implements social and behavior change activities to increase the use of HIV prevention, testing, care, and support services, and encourages positive behaviors that reduce the impact of HIV on communities. Depending on the needs identified, priority groups are provided services directly or escorted, and passive referrals are provided. Components of the One-C intervention include the following:2,3

- Targeted community HIV testing services at hot spots and through mobile and client-initiated approaches.
- Referrals to start ART and linkages to support groups for adherence support for those who test positive.
- Regular household visits to PLHIV and delivery of services including condom education and distribution; support for disclosure; screening and referral for tuberculosis (TB), sexually transmitted infections (STIs), major depression, and malnutrition; education to reduce stigma and discrimination; assessment of adherence to treatment and clinic appointments; and adherence counseling.
- Economic strengthening activities (e.g., village saving and loan [VSL] groups) for vulnerable households, including OVC and their caregivers.
- Prevention services including referrals for voluntary medical male circumcision (VMMC).
- Community fairs that aim to generate demand for existing HIV and AIDS services including condoms, HIV testing and treatment, and VMMC.
- Community action sessions that engage members of the local community in activities to demonstrate their commitment to preventing gender-based violence (GBV) and other harmful gender norms and practices.
- Individual and small group sessions for priority groups to discuss issues that affect their lives in order to adopt positive health behaviors that will reduce their risk to HIV.
- Go! Girls Clubs for out-of-school AGYW to build social assets. Clubs focus on HIV prevention, care and treatment, STIs, GBV, positive gender roles, positive parenting and caregiver skills, norms change, financial literacy, and economic strengthening.
- Promotion of HIV testing among OVC, risk reduction counseling for older HIV-positive OVC, and symptomatic screening for TB, STIs, and major depression.

Mangochi, Mulanje, and Phalombe), where One-C programs and activities are being implemented. This brief focuses on the qualitative research. Project SOAR assessed the extent to which One-C is improving the well-being and decreasing the risk of HIV acquisition among the three priority populations. The research also assessed the well-being of PLHIV, including adolescent girls and young women living with HIV (AGYWHLIV), and gathered insights on program implementation from community resource persons (CRPs), volunteers who implemented One-C’s programs and activities. The primary objectives of the qualitative research were to:

1. Document program recipients’ experiences with the One-C program and whether these experiences impacted their quality of life.
2. Provide a deeper understanding of the barriers and facilitators of accessing HIV care and treatment services among PLHIV and AGYWHLIV and changes, if any, they attribute to One-C.
3. Identify effective strategies to increase access and use of HIV prevention, care and treatment services by One-C’s target populations.

For quantitative findings from the monitoring activity, see the results brief entitled, “Monitoring
HIV Prevention, Care, and Treatment Indicators in Malawi’s One Community Program.”

**METHODOLOGY**

Researchers conducted in-depth interviews (IDIs) from May to August 2018 with eligible participants, who were randomly sampled from a list generated via a household screening exercise. Inclusion criteria were:

- **OVC caregivers:** aged 18 years or older and caring for an orphan or other vulnerable child age 0–17
- **AGYW:** aged 10 to 24 and not currently enrolled/registered in school
- **OVP:** aged 18 years or older and considered a vulnerable population
- **PLHIV:** male aged 18 or older, female aged 25 or older; and living with HIV
- **AGYWHLHIV:** female youth aged 15 to 24 living with HIV

All participants had to be proficient in the relevant local language or English, provide informed assent or consent, obtain informed consent from a guardian if younger than 18, and reside in the study location at least six months prior to the interview.

A total of 141 IDIs were conducted: 9 with AGYW aged 10–14; 26 with AGYW aged 15–24; 25 with OVC caregivers; 25 with OVPs; 24 with AGYWHLHIV; and 32 with PLHIV. Participants selected within each study population had either participated or not participated in the One-C program at the time of the interviews, allowing for deeper insights into the program’s impact. We note where exposure to (i.e., participation in) One-C program activities, age, and district differences emerge during analyses.

Six focus group discussions (FGDs) were conducted with CRPs. FGDs were only held in Blantyre, Chikwawa, and Mangochi (two in each district—one female and one male) because the CRPs were no longer implementing programs in Phalombe and Mulanje at the time of the study. In total, there were 58 participants across the FGDs. IDIs and FGDs were conducted between June and September 2018.

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**AGYW**

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*All 10–14 were, unmarried and did not have any children
**All 10–14 were unexposed

**Knowledge of HIV and SRH**

Although the majority of AGYW had some basic knowledge about HIV, those who participated in One-C programs, including Go Girls! Clubs
demonstrated a greater understanding of HIV and could better identify methods of HIV risk reduction and benefits of HIV treatment. Nearly all exposed AGYW indicated that the information taught by the One-C program was the most beneficial part of being involved and credited participation for their greater awareness and knowledge of HIV. However, both unexposed and exposed AGYW still mentioned common stereotypes and misconceptions about HIV and demonstrated little awareness of treatment as prevention. Exposed AGYW also discussed increased knowledge of SRH, including pregnancy prevention and FP, due to participation in One-C programs.

“The program is good…. It has taught us many things which we didn’t know like dangers of getting pregnant while still young, FP methods for men and women.”
—Blantyre, exposed, age 21

Perceptions of sexual relationships & gender norms
Most AGYW were apprehensive toward men, and all AGYW described fears they held when discussing sexual relationships. They feared getting HIV or pregnancy, dropping out of school (among very young girls), aggressive behaviors and violence from men, and lack of care within relationships. Gender norms and societal expectations play a major role in reinforcing their fears. For example, AGYW from Mulanje and Mangochi discussed initiation ceremonies as a cultural practice where girls learn about gender roles, including women should not refuse their partner’s sexual advances. This has led to men controlling condom use and other SRH behaviors.

“I tell my friends that boy and girl relationships are bad because they can make us pregnant and reject us and we can even drop out of school. They would be going to school while we are at home.”
—Chikwawa, unexposed, age 13

AGYW who participated in One-C described developing a sense of independence and determination to improve relationship dynamics through positive communication and sharing what they learn with their partners. For example, AGYW described discussing FP options with their partners.

“Maybe that time we were being childish or maybe ignorant, but now I discuss with my husband. …he had an issue of sleeping around, …and I would say, ‘This is not alright. If you want to move around, go do other things because you might get infected and leave the children in trouble.’”
—Mulanje, AGYW, exposed, age 24

Health behavior
AGYW aged 10–14, reported not engaging in any sexual relationships, emphasizing parental monitoring and the need to focus on their education as the primary reasons for abstaining.

All but 2 out of 14 AGYW aged 15–24 were involved in a sexual relationship. One-C program participation influenced these women to be faithful to their partners but few used condoms despite a reported and demonstrated increase in HIV and FP knowledge. Most unexposed AGYW reported that they either did not use condoms or they used them inconsistently as well. Married AGYW, especially, did not use condoms because unprotected sexual intercourse was expected within their relationship and they were uncomfortable asking their husbands to use condoms. On the other hand, about half of exposed AGYW compared to one unexposed AGYW described using a FP method such as Depo-Provera.

“It [One C] has changed my behaviors because before I was having sex anyhow, but now I changed [referring to using FP]…to avoid regularly giving birth.”
—Chikwawa, exposed, age 21

One-C programs encouraged AGYW to know their HIV status by testing for HIV. Several AGYW described discussing the importance of HIV testing with their husbands and partners. AGYW also perceived that more people in the community were accessing HIV testing services as a result of One-C programs.

“…at the time I started One Community, I …sat with my husband and explained what we are going through [learning] and that...”
if we could do this, things will change and we will be having a good life.... My husband was afraid of getting tested but from the time I was going there, I wasn’t hiding. I would tell my husband everything...."

—Mulanje, exposed, age 24

**Ability to save money to meet basic needs**

Most AGYW aged 10–24 indicated that the biggest challenge they faced in their daily life was meeting their basic needs, which was mainly attributed to their or their families’ inability to find stable and reliable work. While piece work (informal, short-term [e.g., a few hours or days] work, such as mowing someone’s lawn, helping with harvesting, or handwashing clothes) offered older AGYW the opportunity to earn money, it hardly provided the stability or finances necessary to purchase basic goods and save for the future. Although most AGYW desired to be self-reliant, lack of available resources made achieving this difficult.

"But the main issue I can say is finding a reliable source to be getting money."

—Mulanje, exposed, age 22

"The thing is that for us to find money here, we wait until the rain falls so that we go and plant soya. Now there is nothing that we depend on."

—Phalombe, unexposed, age 22

AGYW, who participated in One-C’s VSL groups, expressed satisfaction with the groups and explained that the ability to save and borrow money assisted them in meeting some of their basic needs.

"If you have nothing in the home like home necessities, you can go and borrow money from the Village Bank so that you can save the home."

—Mangochi, exposed, age 18

However, some AGYW stated that being members of the VSL groups were at times difficult due to lack of financial security and constant need to find money to contribute to the group. AGYW also noted having a hard time paying back the loans and wished that One-C had initially invested money into their village bank to help their savings increase.

"Sometimes I would be absent [from VSL] due to lack of money and I felt it was better just to leave it. When I have no money, what do I do there?"

—Mangochi, exposed, age 18

**Aspirations for the future: returning to school**

The majority of out-of-school AGYW reported that they would like to return to school and complete their education, but they faced different barriers based on age aside from financial challenges. Adolescent girls aged 10 to 14 reported lack of parental encouragement. AGYW aged 15 to 24 described childcare, marriage, and even feeling too old to go back to school as primary barriers to returning to school.

"On my own to achieve [those plans] it is difficult, that’s why I am still stuck here, but if I found a sponsor, then I could be assisted in terms of money."

—Phalombe, exposed, age 24

Overall, exposed AGYW did not perceive that their involvement in One-C programing aided them in returning to school, primarily because school fees and materials were not available.

"I can’t say that I will achieve [going back to school] because I don’t have any assistance... [such as] school fees and other important things that can be needed."

—Mangochi, exposed, age 23
Participant experiences from One Community program in Malawi

Overall program perception and impact on future outlook

The majority of exposed and a few unexposed participants described One-C as having a positive impact on themselves, and/or those in their community. While unexposed participants had not participated directly in an One-C activity, they knew of them and attributed positive changes they were witnessing to the program.

Eleven exposed and six unexposed participants described feeling positive and hopeful about their future. The most common reasons attributed to a positive outlook were knowledge of HIV status, feeling healthy and being able to meet their basic needs. In some cases, a positive outlook was associated with One-C interventions, specifically an increase in knowledge about strategies to prevent HIV.

> When I say that I have a bright future I mean that 1) I got tested and was found negative...; and 2) the business that I run, helps me to take care of my everyday needs.

—Phalombe, exposed, age 38, male

However, 12 participants (8 exposed, 4 unexposed) expressed feelings of uncertainty and worry when it comes to the future. In particular, participants worried about being able to find enough food, and about maintaining their health. Of the 25 OVP respondents, one third expressed hopelessness; they felt that they do not have the support or resources to overcome the challenges that they face.

> When I look into the future, I see that the world is coming to an end. It is up to you to tell me the things that I have to do to ensure that my future is going on.

—Mangochi, unexposed, age 48, male

HIV knowledge, testing, and behavior change

Participants described the market place and places where they do piece work—short term (e.g., a few hours or days) temporary work—as locations of high risk for HIV transmission. Both female and male...
participants described gender dynamics that place them at increased risk of HIV acquisition. Female participants noted feeling pressured by men to engage in sexual relationships in exchange for money to boost their business. Male participants described feeling tempted by women at the market, especially when female customers are unable to pay for items.

“"A man came and said that I had to stop doing this business because it was too small for me to engage in…a woman of my caliber cannot do that type of business…. He said he will give me K10,000 and go to the rest house for sexual intercourse…. So if you ask me about the marketplace…there are so many dangerous things."—Chikwawa, unexposed, age 42, female

Both exposed and unexposed participants had knowledge of HIV prevention and risk reduction strategies. They identified One-C in addition to radio, television, hospitals, and awareness campaigns as information sources for HIV. Two-thirds of participants connected positive behavior change among themselves and in their communities to the One-C programs, especially One-C resource persons who encouraged community members to live healthy lives and access health services. Participants stated they developed more positive attitudes toward HIV testing and other existing services, and more people were testing for HIV. They also described utilizing informal and work spaces to share knowledge about HIV prevention with their peers. On an individual level, participants perceived that their peers were beginning to change their risk behavior with individuals having fewer sexual partners.

“"Many people got tested [for HIV] due to the coming of One Community."—Blantyre, exposed, age 24, female

Stigma toward PLHIV
Exposed participants felt that the livelihood and well-being of PLHIV had improved as a result of One-C programs, and as such, stigma and discrimination toward PLHIV had gone down. Some participants even stated that HIV-positive people have an improved will to live, and speculated that they did not feel burdened by HIV because of the support provided by One-C.

“"Today, through the One Community initiative people are being encouraged that being found HIV positive does not mean the end of one’s life. This shows that One Community has brought hope to all those people that had misconceptions of HIV/AIDS which could lead to committing suicide."—Blantyre, exposed, age 64, male

However, unexposed participants expressed stigmatizing attitudes toward PLHIV. A few described PLHIV as living irresponsibly, not using protection during sexual intercourse and at times, intentionally trying to transmit the virus.

“"It’s not just them, with their loose life that go and infect others as well…. When they discover that they are infected they say that, ‘Should I be alone? I have to infect others so that when I’m dying I have to with many others.’ So they go about spreading the infections."—Phalombe, unexposed, age 31, male

Income challenges and meeting basic needs
Nearly all OVP respondents described a lack of income to meet basic needs and a lack of capital to boost their businesses, resulting in the frequent stopping and starting of businesses. As such, OVPs perceived their job and work as unstable and unreliable. Unreliability was also related to seasonal labor, when jobs changed based on the season, what work was available, and the failure/success of the harvest. Crop failure and drought can lead to a bad harvest while commodity surplus triggered competition and the lowering of prices for goods. For the latter, participants described throwing away goods and returning home without enough income to afford food.

“"When we have done our business and go home you find that the money that one was supposed to make from the business
is not enough which gives me concern because the plan is to make business and get something. The worry is that how can my business move forward if I am always having little money.

—Mulanje, unexposed, age 35, female

Participants who participated in the VSL programs acknowledged the program benefited them by allowing them to save money. However, this money was only enough to meet very basic needs. The loans they were able to take were not enough to truly establish a strong and secure business. They indicated that One-C or other programs should provide capital for their businesses.

“...What I am thinking is that if we had some NGOs who would be giving out some money as starter money (capital), yeah! So that we should be starting some good businesses which would help to take care of that household. That would be very good.

—Phalombe, exposed, age 24, female

OVC CAREGIVERS

Learning how to manage life’s many problems
The majority of caregivers expressed concern about their ability to provide adequate care for OVC in their household, with both exposed and unexposed participants acknowledging the harm that discrimination toward OVC can have on their well-being. Caregivers were concerned about the future of the children under their care; especially their educational advancement and having their needs met.

“The concerns I usually have is on how best I am going to take care of these children until they grow into adults. And for these to grow, what should I have to do? Because to grow, the child needs to eat, proper care, bathing with soap, and has to be sent to attend school. With this poverty, we fail to do some of these things, but I have always

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thought that it is important to take care of orphans.

—Blantyre, exposed, aged 60, female

Caregivers valued One-C programs because of the knowledge they gained on how to live healthier lives. Participants indicated that they had a stronger sense of HIV prevention strategies, ability to care for themselves and manage their HIV status (if positive), connection with their children, and ability to support their children’s development. Specifically, caregivers expressed gratitude for the work of the CRPs, noting their dedication and commitment to educating and guiding them through the process of accessing HIV care and managing their and their children’s treatment.

"The One Community visited me and told me that with the way my health was, I should undergo HIV screening. I was very open to them; I told them ... I was already... positive with HIV and these people kept on supporting and encouraging me through their counseling. I can say that I was very happy as I was being told what to do, that is why I am saying that the program affected me and I am being encouraged. I am living happily with the disease.

—Mangochi, exposed, age 23, female

Caregivers also stated that the relationships between themselves, family members, and OVC had improved due to the increased support provided by One-C, including the alleviation of stress through receiving support and guidance, education around the rights of children, and proper treatment of OVC. As a result, they cited positive change in the behavior of their children, as well as their own behavior and treatment of the children under their care.

"The organization has taught us how to look after the orphans and our own lives. We have been taught things we did not know. In the past we knew very little on how to properly care for our children.... I am personally thankful for this organization, it appears the organization is very useful to the community.

—Blantyre, exposed, age 60, female

Income challenges & meeting basic needs

Caregivers of OVC expressed challenges when it comes to maintaining a stable income, often due to unreliable sources of income and the constant need to “hunt” for daily work. When work is found, pay is minimal and given the high demand for work in Malawi, most people earn between MK1,000 and MK5,000 (between $1.38 and $6.88) maximum for a contract job. They also noted having to rely on others for income assistance and not feeling in control in their ability to earn money.

"Sometimes we engage in small scale business at the market... If not business, then my husband go to the mountain to cut firewood for selling... at other times we cut grass, we find customers and sell it to them. When everything fails then we have to go out and do some piece work on people’s farms to buy food and clothes for us and the orphan children.

—Chikwawa, exposed, age 50, female

Many caregivers found the VSL programs especially valuable as it provided an opportunity to save money and take out loans for items that they may not be able to afford otherwise. This contributed to alleviating the stress that some caregivers faced.

"I can say that after One Community arrived, things have become better because sometimes it happens that there is no piece work but when we go to the village banks, they lend us some money to buy food.

—Mangochi, exposed, age 25, female

However, caregivers viewed participation in VSL programs as not necessarily providing the support or resources needed to change their experiences or realities. Their sources of income remained the same and finding work remained a problem. Several caregivers expressed an interest in One-C providing additional loans or capital so they can invest in a business, along with saving money for the future. In this way, participants would be able to alleviate the stress of constantly struggling to survive.
What I think in my life is that they should help me by giving me money to start a business. That means that when I am doing business on one hand I will also be depositing something in the Village Bank and my children will not suffer in school resources because I will be finding money and may not lack things in my life.”

—Mangochi, exposed, age 23, female

### PEOPLE AND ADOLESCENTS LIVING WITH HIV

#### Barriers to healthcare and HIV services

**Food insecurity**

Both PLHIV and AGYWHLHIV experienced inconsistent work and challenges to obtaining enough income to meet their basic needs, which often had a direct impact on food security. PLHIV and ALHIV frequently discussed the lack of food within the context of ART. They were fully aware that they should eat when taking the medication. However, many PLHIV and AGYWHLHIV were unable to do so because food was simply unavailable. When asked what type of HIV-related assistance was needed, participants commonly responded that they needed food provisions or better sources of income so that they could purchase food.

“Like I said, there are some people who when they don’t eat, they don’t want to take their medications. They say that they don’t feel well when they take the medications without eating, and they claim that it is better that they die than take their medications... It would be better if they received maize, soya beans, and cooking oil in order to help them.”

—Mulanje, PLHIV, exposed, age 28, female

#### Stigma and discrimination

All PLHIV and AGYWHLHIV described having observed HIV-related stigma and discrimination within their communities. Experiences of stigma and discrimination appeared to have a profound effect on AGYWHLHIV, who sometimes reported being “laughed at” by their peers because of their HIV

### PLHIV and AGYWHLHIV characteristics

<table>
<thead>
<tr>
<th>PLHIV and AGYWHLHIV characteristics</th>
<th>PLHIV N=32 %</th>
<th>AGYWHLHIV N=24 %</th>
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status. AGYWLHIV perceived lack of support from family after receiving an HIV diagnosis as a form of stigma or discrimination. AGYWLHIV also described concerns about being accepted in the community, such as the likelihood of getting married because of the gossip and other forms of stigma and discrimination they experienced.

“People talk about your HIV status. People comment that you are stupid. If people see you doing something, they will remind each other that you are HIV positive. When you hear all these comments, you get discouraged.”

—Phalombe, AGYWLHIV, exposed, age 22

There were also concerns that stigma and discrimination could hurt the community, such as people avoiding HIV testing for fear of being stigmatized. Recommendations for addressing stigma and discrimination include engaging with governmental and nongovernmental entities within the community, and monetary fines of community members who refused to engage in equal treatment. PLHIV, who were older, also appeared more accepting of their status as compared to AGYWLHIV.

“Stretch out the hands to each other with full support and full of love. No one should discriminate anyone again. Everyone is equal, no one should say that this is HIV, that HIV is sick, I am not. I want to go and be treated, I have the right to be treated like this.”

—Phalombe, PLHIV, exposed, age 29, female

Facilitators to healthcare and HIV services

Health behavior and access to healthcare

Both PLHIV and AGYWLHIV recalled consistently accessing healthcare and taking ART and other medications as prescribed since learning that they were HIV positive. The most common motivation behind accessing routine care and adhering to medications was acceptance of their HIV status, and a desire to live a healthy life. Additionally, those that were unable to go to the hospital themselves enlisted support from a guardian to ensure that they’d adhere to treatment.

“I do not fail to drink medicine [referring to taking medications with water]. I always drink, even if I will face a problem by doing that, I will drink.”

—Mulanje, AGYWLHIV, unexposed, age 24

Livelihoods also influenced where participants accessed HIV care and treatment services. Across the districts PLHIV and AGYWLHIV chose to access HIV care and treatment services at the medical facility closest to where they lived. This decision was driven by a lack of financial resources available for traveling to facilities that were farther away. Trips to medical facilities tended to be time consuming and could take as long as a full day roundtrip. This was of particular concern for PLHIV and AGYWLHIV for when there might be a medical emergency or need to enlist the help of a family member in obtaining medication from the facility.

Participants expressed several concerns regarding health facilities such as long wait times, poor interactions with healthcare staff, and privacy. However, these concerns did not deter some participants from routinely accessing HIV care and treatment services. Instead, PLHIV and AGYWLHIV perceived that those who traveled farther away to access a health facility did not fully accept their HIV status.

“They just feel lazy, and some are ashamed to go and seek care because they are afraid if they tell them that they have the disease, their life will be troubled.”

—Blantyre, AGYWLHIV, unexposed, age 22

Multilevel support is essential for access, retention, and adherence

Participants frequently described receiving support from family members to continue receiving treatment and remain adherent to ART. Most participants believed that encouragement and counseling from their families was essential for helping other PLHIV and AGYWLHIV with access and adherence. Moreover, many PLHIV and AGYWLHIV
perceived the community, as a whole, should have a role in promoting HIV prevention, care access, and care retention.

“The wife is the guardian. I will talk about my case, for example. My wife always reminds me if I have taken my medicine so that we combat this disease, because sometimes I can forget. She has to remind me.”

—Mangochi, PLHIV, unexposed, age 53, male

PLHIV and AGYWHLHIV frequently described positive experiences in their interactions with some healthcare personnel, indicating that the encouragement, counseling, and education they received motivated them to stay in care and practice risk reduction behavior. Participants also saw visiting homes of HIV-positive people who missed medical appointments to be an important and effective strategy for adherence and remaining in care.

**HIV-positive status provides an opportunity for a new and improved life**

Many PLHIV and AGYWHLHIV expressed that receiving an HIV diagnosis gave them a new perspective on life and gave them an opportunity to have a longer and improved life. This was in large part due to receiving consistent healthcare and taking medication as directed, resulting in fewer health challenges and feeling stronger than prior to receiving an HIV diagnosis. Some PLHIV reported using their improved health as a way to help encourage other community members to seek HIV testing.

“Now they envy us with the way they see us. They see us doing our work and then together say, ‘Look that one takes medicine, but...her health is good’.... So we know that in their thoughts they were thinking badly about us, but now they are envying us for our persistence in taking the medicine.”

—Blantyre, PLHIV, unexposed, age 60, female

**One Community impact**

**Education and encouragement as motivation to stay in care**

Some PLHIV and AGYWHLHIV noted that the continued encouragement provided through One-C programs provided much needed support to remain motivated to stay in care. It also helped participants change their attitudes and behavior toward using condoms as a preventative measure against transmitting HIV.

“The program is doing well in encouraging women to be in groups, where they discuss about HIV. We were behind before One Community came. People would not drink medicine. Some were hiding. It is now that things are improving. We have lost so many lives before One Community came.”

—Mangochi, PLHIV, exposed, age 53, male

Some PLHIV and AGYWHLHIV noted that One-C helped address stigma in their communities and alluded to the program’s activities providing a space in which stigma was not a concern. This was reflected in the counseling they received from CRPs, and the fact that activities were open to the entire community, and not just those who were HIV positive. However, One-C did not totally erase stigma in the communities, as some participants still felt that there needed to be greater confidentiality from CRPs when they speak with other community members.

“They told us not to stop drinking medicine. They said that even if we were found with HIV, it’s not the end of our life. They said that this is our future, and they encouraged us to continue taking medicine.”

—Blantyre, AGYWHLHIV, exposed, age 24

**Improved outlook on life is a valued benefit**

For most AGYWHLHIV and PLHIV who participated in the program, benefits went beyond education and encouragement related to their physical health. The program also helped many of them improve their mental health and develop and/or maintain a positive outlook on life. Rather than seeing their diagnosis and ART as a burden, participants perceived it as an opportunity to have
a life characterized by good health and strong relationships. Many PLHIV and AGYW-LHIV who participated in One-C specifically attributed this outlook to their engagement with the program.

"...One Community is doing well because it is giving us a good vision of the direction where we are heading to. Because if it was not for that, if One Community did not exist, as I have said, then my marriage couldn’t last till now. My husband and I could have been divorced. I could have been with another person."

—Phalombe, PLHIV, exposed, age 29, female

Negative outlooks were most common among unexposed participants, who often had a mixed outlook on life in which they were positive about their current state of affairs, but worried about the future.

"I just worry. I just stay. What else can I do since things just happened? ... My future. I just think about that I dropped school early. I didn’t proceed... My future is not well because I am taking the medication."

—Chikwawa, AGYW-LHIV, unexposed, age 22

### Community Resource Persons

<table>
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</tr>
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**Preparedness to provide HIV services**

The CRPs who implemented One-C programming had prior knowledge and expertise in topics, including safe motherhood, self-reliance strategies (savings), HIV, FP, counseling on various health services, and child rights. The CRPs described gaining additional essential technical knowledge and skills through training provided by One-C that allowed them to effectively sensitize, guide, and advise members of One-C’s target populations on HIV prevention, care, and treatment. Essential knowledge and skills identified included public speaking, evaluation skills, interactive and effective engagement strategies, community entry tactics, financial management, and team coordination. CRPs were also trained to identify resources within their communities that could further assist the program participants. CRPs described building relationships with the community chiefs and health centers as a way to ensure that participants were cared for and supported, even when they were not around.

"When One Community started, it didn’t just start. We were taken to undergo training where they trained us on how we can work in the communities. This expertise complemented the already existing skills that we have; we are veterans in terms of health work because we have worked with other organizations."

—Chikwawa, male

**Barriers to accessing HIV prevention, care and treatment services**

**Fear of stigma and testing positive**

CRPs recounted that fear of stigmatization and testing positive were key challenges to testing for many community members they encountered, and stigma also was a challenge for PLHIV to access treatment services. The latter experienced stigma from the community and in some health care settings.

"Sometimes people are afraid to get tested. Many people think that they will be found positive looking at how they are. Moreover, they consider that as they will..."

Project SOAR Results Brief | 13
be moving out of the VCT room people will
discover that they have the virus.
—Blantyre, male

Misinformation and myths
CRPs described working diligently to correct
misinformation and dispel myths associated with
HIV prevention and risk reduction that permeated
throughout the communities they serve and acted
as barriers to HIV services. Misinformation focused
on male circumcision and condoms while belief in
witchcraft prevented some from accepting their HIV
status.

When we started conducting small
meetings in the villages concerning
male circumcision, it showed that there
were a lot of myths about male circumcision.
They thought that the health workers were
benefitting by using the foreskins for other
purposes.
—Blantyre, male

Food insecurity
CRPs identified lack of food as one of the main
reasons for nonadherence to ART among PLHIV.
Providing referrals to organizations who could
provide food was important to retaining some PLHIV
in care.

When it comes to the food then it is
very difficult, we can encourage them
but then they can have no place where they
can get the food, so this is a difficult situation.
So they can fail that they should accomplish
this [referring to ART adherence] because they
are not able to find these things [referring to
food].
—Blantyre, female

Poor quality care at health facilities
CRPs reported that community members
complained of continued challenges at some health
facilities, reporting poor interactions with health care
staff, delays in dispensing drugs, lack of referrals
to hospitals, lack of confidentiality and privacy in
counseling, and discrimination against PLHIV in the
health facilities.

Some hospitals are still using the
old system of having a line that is
strictly for people who receive ART but in
some facilities we sit like we have here, so
that everything will be known inside whether
it is malaria it should be known inside the
diagnosis room. In this case, no one could
say this one has taken this kind of medicine.
These things of grouping people that these
are for malaria and these are for this, in some
hospitals they are still there, not changed.
—Mangochi, male

Strategies to increase access to and use
of HIV prevention, care and treatment
services

Home and community-based services
A successful strategy expressed by CRPs for
increasing access to and use of HIV services
implemented by One-C was reaching people where
they were and providing a range of services and
programs. CRPs noted that home-based HIV testing
and counseling was critical in alleviating stigma
and fears of testing and providing the required
counseling to link individuals to treatment if positive.
Additionally, tailoring service delivery to community
members’ needs allowed CRPs to be more effective
in reaching them with HIV prevention and treatment
messages and services.

The challenge that we have is for
someone from very far to get tested
and go back; they see this as a difficult thing
to do. As such, many people just hold on to
the referrals that we give them without using
them. This coupled with the fear of being
found HIV positive, results in the people just
giving up. Otherwise community-based testing
was good because a couple would be tested
at the household alongside their children. As
such, the process was private and confidential
because it was done at the household level.
—Chikwawa, male
Referral and follow-up system
CRPs noted that an efficient referral and follow-up system that links individuals from household and community-based testing to HIV treatment services was crucial for early treatment initiation and continued adherence. Important aspects of the system included having appropriate referral forms to ease client burden at health facilities, involving clients in decision-making about where they would like to seek care, and timely follow-up of clients who do not use referrals.

“Sometimes we would write a referral…without asking the person the choice of the hospital where he would like to go. If we do that then we have complicated things. We need to have beneficiary consultation so that we hear where they would choose to go and receive their medications.”
—Mangochi, female

Support groups for PLHIV
CRPs described support group membership and interaction as key influencers of people in the community accepting their HIV status, and starting on and adhering to ART. Support groups aided in improving the mental well-being of PLHIV by allowing members to openly discuss challenges, share new knowledge, and motivate each other. Provision of referrals during support group meetings helped prompt attendance at the health facility and helped defaulters resume treatment. However, CRPs noted that women benefit more from support groups than men due to their regular attendance at meetings.

“...One Community has helped people who were in darkness to see the light...see the advantages of belonging to groups. Many people used to hide and could not be open to join groups. ...we have trained the people and the people have learnt that being in groups helps the people to be open and free in terms of what they do.”
—Chikwawa, male

Perceived impact of One-C
CRPs perceived that the One-C programs had a positive impact on changing certain individual- and community-level attitudes and behaviors. Among OVC caregivers, CRPs perceived less discrimination toward OVC, improved household hygiene, improved child management and relationships, reduction in abusive treatment of OVC, continuation of schooling among both biological children and OVC, more peer education and interaction, and a ban on early marriages with support from chiefs and elders.

“The other thing is that there were a number of different examples of cruel treatment of children. This could be ill-treatment from a parent to a child, but the parent would not know what they were doing is a form of ill-treatment. But with the coming of One Community some of these cruel treatments have stopped as people are now aware that if I will do this then I have committed cruelty on the child.”
—Chikwawa, female

Among AGYW, CRPs perceived an increase in the number of abuse cases being reported, greater awareness of chronic diseases, less stress, increased use of FP methods, reduction of risky behaviors, enhanced awareness of the importance of knowing their HIV status, reenrollment in school, and finally, reduction in the number of school dropouts.

“What has worked well is the issue of FP, where it has been observed that many people are using FP methods.”
—Mangochi, female

Among OVPs, CRPs perceived increased receptiveness to counseling and reduction in risky behaviors. They noted that vendors were happy with the HIV lessons, requests for condoms increased, more OVPs accepted HIV testing at home, and more of those who tested positive started medication.

“The thing is that they [fishermen] are far from their families and women who want to buy fish might go there, and we tell
them when these women are coming please make sure that you use a condom to protect your life.

—Chikwawa, female

Among PLHIV, CRPs perceived increased comfort in disclosing status to others once trust is built, improved acceptance of HIV testing at hospitals, increased adherence, and improved overall health after counseling.

Whenever people tested for HIV they would just stay in their homes. However, we brought the PLHIV to be in groups so that they could encourage each other about their lives. They are now able to come out in the open for people to know their status.

—Blantyre, male

**CONCLUSIONS & RECOMMENDATIONS**

Findings from this study reveal a number of strengths of the One-C program as well as areas that can be strengthened.

- The inability to meet basic needs and find stable work has contributed to engagement in behaviors that increase the risk of HIV, such as women in the market place who have sex to sustain their business. Village banks developed through the VSL under One-C has allowed participants to save and meet some basic needs. Efforts should be made to strengthen and expand the VSL groups. Efforts should also be made to connect or partner with investors, such as private companies, to expand village banks that enable participants to grow their business, save money for the future, and meet their daily needs.

- Community-based delivery of HIV and SRH information and services by knowledgeable CRPs who were viewed as trustworthy and caring played an important role in participants’ ability to adopt strategies to reduce risk and prevent HIV, including testing for HIV and linking to treatment. Tailoring services for populations, such as Go Girls! Clubs for AGYW, support groups for PLHIV, and one-on-one meetings for OVPs, also contributed to reaching One-C’s priority populations. Efforts should be made to sustain the CRP model and the services they provide.

- Poor-quality, facility-based services (e.g., poor interactions with staff, lack of confidentiality) serve as a deterrent for accessing HIV services for some PLHIV. Yet, other PLHIV report receiving high quality care at some facilities and from certain providers. Assessments should be conducted to identify facilities and providers that provide both poor and high-quality care. The strategies of high-quality facilities and providers should then be promoted among those facilities and providers providing poor quality care.

- Stigma and discrimination remain a major barrier to accessing HIV services, including testing and treatment uptake. Although some reduction in stigma was perceived due to One-C activities, efforts should be made to assess and measure levels of HIV-related stigma at health facilities. Where needed, proven stigma reduction interventions and strategies should be provided to health care staff.

**REFERENCES**

2. One Community. https://ccp.jhu.edu/projects/one-community