

Together we stay on: Supporting retention in care among people living with HIV in Mozambique

Implementation story from the
ADPP Mozambique Stay On project
supported by Aidsfonds (2020-2023)



Background and context

Barue district is located in Manica province, in the central region of Mozambique. The HIV prevalence nationally is 15.4%.¹ In Manica province it is estimated that 17,455 people are living with HIV (prevalence 7.9%).² Dropouts from the care continuum are common, mainly driven by economic challenges (lack of funds for transport to the clinic and inadequate nutrition), but also a continuing fear and stigma around HIV. The project focused on ART adherence and retention in care, with a particular focus on adolescent girls and young women aged 15-25 years.

ADPP Mozambique took a holistic approach to retention in HIV care and treatment within the Stay On project, understanding the complex dynamics that affect antiretroviral therapy (ART) adherence.

The story of Sarah and Esther

Far from the health facility, in a rural community outside Catandica, a family lives together on a small compound. The houses are roofed with grass and outside sits a woman, Sarah, who has been sick for longer than she can remember and neither she nor her family know what to do.

Esther, an activist from the ADPP Stay On project visits the family during door-to-door mobilisation. She tells Sarah about HIV. Sarah is scared to test; she knows of people who have died because of it. But she is also tired of being sick and Esther tells her that even if she is HIV positive, there is hope of a long and healthy life. Sarah decides to test, and her test comes back positive.

Sarah starts taking her HIV medication, but feels dizzy and nauseated. She wants to stop taking them, but Esther visits her and encourages her to continue, telling her that the side effects will reduce over time. Esther encourages her to eat nutritious food to improve how she feels.

Slowly, Sarah starts to regain her strength and weight. Esther tells her she can join a positive living group, meet with others who are also HIV positive, learn about how to take care of herself. She explains that the group also does some savings and loans so she can put money aside for transport to the clinic and even take out a loan to start a small business when she is ready.

¹INSIDA (2022), Mozambique Population-Based HIV Impact Assessment: Summary Sheet.

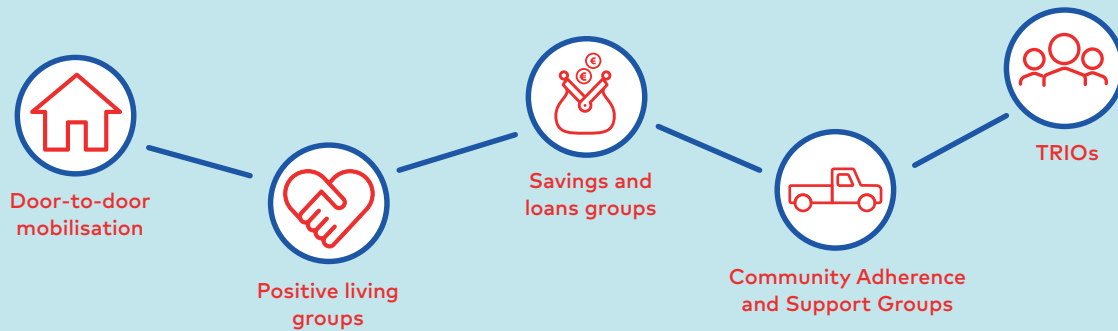
²ibid

Stay On project in Mozambique


The main pillars of the project were:


1. Empowerment of people living with HIV, through family and community-based support mechanisms to overcome stigma and discrimination and enhance treatment literacy.
2. Collaboration with community leaders and other influential people to share knowledge about HIV, mobilise for acceptance and support for people living with HIV, and end stigma and misconceptions.
3. Economic empowerment of people living with HIV for improvements in nutrition and food security.
4. Education and sensitisation of health workers to provide rights-based and user-friendly support for people living with HIV in their diversity, particularly for adolescents.

Within the project model there were five key interventions that functioned as support mechanisms:





 **Door-to-door mobilisation** – Activists and peer navigators were trained in partnership with OMES, a community-based organisation working to improve retention in care within Barue district. Each activist was linked with a health facility and conducted door-to-door mobilisation, patient accompaniment/navigation, group support mobilisation and health education. Through door-to-door mobilisation, activists met with people living with HIV, provided them with health education and counselling, and mobilised them to join support groups.

 **Positive living groups** – are one of the two primary support mechanisms for people living with HIV. Positive living groups were made up of people living with HIV who met together to talk about adherence, to receive education on health and nutrition and to support each other when challenges to adherence arise.

 **Savings and loans groups** – over the course of the Stay On project, many positive living groups also functioned as village savings and loans associations to provide an opportunity for members to improve their economic status through regular savings and access to loans for investment in small businesses and income-generating activities. Access to savings and loans improved the ability of members to pay

for transport to the health facility to continually refill their antiretroviral medications and to routinely monitor their health status (CD4 count and viral load testing).

 **Community Adherence and Support Groups (GAACs)** – GAACs served as a support mechanism for people living with HIV who had been adherent for six months or more. Within these groups, a differentiated service delivery model was used for group members to arrange for refills of ART from the health facility. This reduced the costs of transport and time needed to refill medications each month and increased the likelihood of adherence.

 **TRIOs** – are the other primary support mechanism for people living with HIV. TRIOs served a similar purpose to GAACs but were made up of one person living with HIV and two people who they trusted and felt close to. These people could be family members, friends or other people living with HIV. TRIOs formed a small group to support adherence, problem solve when issues arose and to continue encouraging people living with HIV to maintain their health. Many people living with HIV joined both a positive living group and TRIO, but some chose only one. Both types of groups were supported by activists.

Community-clinic collaboration was a critical component of the Stay On project. Activists were linked with health facilities to identify people living with HIV through door-to-door mobilisation and once identified, people living with HIV were either linked to care or reintegrated into care. Health facilities provided comprehensive ART services which were supported by community-based interventions.

The impact

Project participants in focus group discussions repeatedly emphasised the importance of the changes in their health status that they had experienced. By regaining their health, their fear had reduced, they had renewed hope of a healthy life, and they could work and provide for their families. A secondary but still critical benefit of Stay On was the feeling that they were no longer alone; embedded in a 'family' through a positive living group or TRIO, and feeling that together, they could maintain adherence and in so doing, be healthy again.

Sarah's future

Sarah joins a positive living group and finds all the things that Esther promised – health education, support, savings and loans. But she finds something else she didn't expect – she finds a family. Sarah feels no longer isolated, no longer dealing with her status on her own. She is together with others who are on HIV treatment and as a group, they support each other to continue to adhere so they can live full and healthy lives. Sarah starts to have hope for her future.

The project achieved the following results:

- **9,524** people living with HIV were supported:
 - **3,466** people who were newly diagnosed and
 - **6,058** who were reintegrated into care
- **36** activists and **10** peer navigators were trained
- Community-clinic collaboration with eight health facilities to improve adherence to ART
- **4,099** people who tested positive for HIV were identified and mobilised to join community-based support structures:
 - **2,478** TRIOS were formed
 - **226** GAACs
 - **72** positive living groups made up of **393** members
- Over **4,000** people participated in community dialogues to raise awareness on HIV and reduce stigma and discrimination
- KUYAKANA developed a Retention and Monitoring Guide for network members to improve adherence and retention. They also implemented quarterly meetings to review advocacy needs, support networks of people living with HIV and work strategically with the Ministry of Health within Manica province.



Lessons learned

TRIOs provide an early support mechanism for treatment adherence. They are relatively easy to form as people living with HIV choose two people they trust and have a relationship with to support them. TRIOs are especially valuable early on in their ART journey.

TRIO members must have a good understanding of treatment literacy to provide effective support.

ADPP found that even if people living with HIV had access to ART, support mechanisms to increase the likelihood of adherence, without education on treatment literacy, many people living with HIV still missed doses or took ARVs irregularly which contributed to unsuppressed viral load. Investing in training and capacity building of TRIO members supported better understanding and adherence.

Positive living groups contribute to reduced isolation and stigma. Participants in positive living groups experienced many benefits from being part of a group – reducing isolation and stigma, feeling connected to and supported by peers, and some even described their group as being part of a 'family'.

Positive living groups that are also integrated savings and loans groups are more sustainable and beneficial in the long-term. Integration of savings and loans into positive living groups contributed to economic empowerment, addressing the very pressing economic challenges that created risk of ART dropout. Access to savings and loans contributed not only to improved income, but to reduced self-stigma and a vision for the future, which supported treatment adherence of 97% among project participants (4,099 people living with HIV). In 2021 average treatment adherence in Manica province was 87%.

Activists provide a critical link between people living with HIV and the continuum of HIV care and treatment.

Activists conducted door to door outreach using a list provided by the health facility of all of the people living with HIV who had recently tested positive or who had dropped out of care. Many participants said that the outreach from activists convinced them to join support groups where they were able to improve adherence and retention in care.

Challenges and recommendations

1. Many activists and peer navigators are continuing their work as volunteers since the project has phased out, but this support will reduce over time as they have other commitments. It is recommended that from the project's inception, they are supported to integrate into the health system where possible. Engaging with the government to embed activists into the existing structures and supporting activists through participation in village savings and loans associations may create more sustainable services for people living with HIV.
2. Many savings groups in the project have started fairly recently. Savings are starting to accumulate, and members are taking loans, but income-generating activities are still at an early stage. Additional training is recommended to strengthen income-generating activities and to ensure that they provide profit for people living with HIV to sustain them over time.
3. Hotspot areas in Barue district continue to need support. There are mining areas where female sex workers are active and where prevalence rates are estimated to be well above the national average. As a transport corridor, Catandica is a key area for HIV prevention, treatment and care as a contribution to overall national reduction of HIV and meeting of global targets. It is recommended that continued support be provided for ADPP community-based partners, KUYAKANA and OMES who can continue reaching out to this key population.

What's next?

Many households in Barue live in poverty and struggle to meet their basic household needs. Savings and loans groups provide an entry point for improved income and retention in care, but there is a need for capacity building and support of groups and income-generating activities to create sustainable small businesses that can provide an income for families in the long term.

Continuing to identify people living with HIV through the outreach of activists is critical. The project has reached a high proportion of people living with HIV, but according to the District Health Officer, there are many more who need the same support. In addition, key populations such as female sex workers are in need of tailored interventions to mobilise them to test for HIV, join support structures and link them into the continuum of HIV care and treatment.

About ADPP Mozambique and partners

ADPP Mozambique is a Mozambican non-governmental organisation established in 1982 and a member of the Federation Humana People to People global network.³ ADPP Mozambique focuses on projects in the areas of: Quality Education, Health and Wellbeing, Sustainable Agriculture, and the Environment.

Website: <https://www.adpp-mozambique.org/>

KUYAKANA is a national network of women living with HIV. It served as a community-based partner for ADPP advising on project implementation and ensuring that the needs and voices of people living with HIV remained at the forefront of the project.

OMES is a community-based partner for ADPP who work to mobilise female sex workers to test for HIV, to link them to care and to reintegrate those who had dropped out of care. OMES provided support to train activists and peer navigators within the Stay On project.

³ The Federation Humana People to People is a global network established in 1996 and made up of 30 independent member associations located across Africa, Asia, Europe, North and South America