

Thandizo

An approach to support young people living with HIV in Malawi with treatment adherence

The Thandizo approach supports young people with adherence to HIV treatment through the Thandizo mobile app and support groups. A pilot project was implemented in Chikwawa and Mangochi districts of Malawi. Evaluation of the pilot proved the Thandizo approach to be successful in improving treatment adherence and (mental) health of young people living with HIV (10-24 years).

To further test and improve the Thandizo approach and to roll out to other districts in Malawi and beyond, investments are crucial. For all young people with HIV to stay on treatment so to ensure they can live healthy and productive lives.



Community health volunteer in conversation with a young person

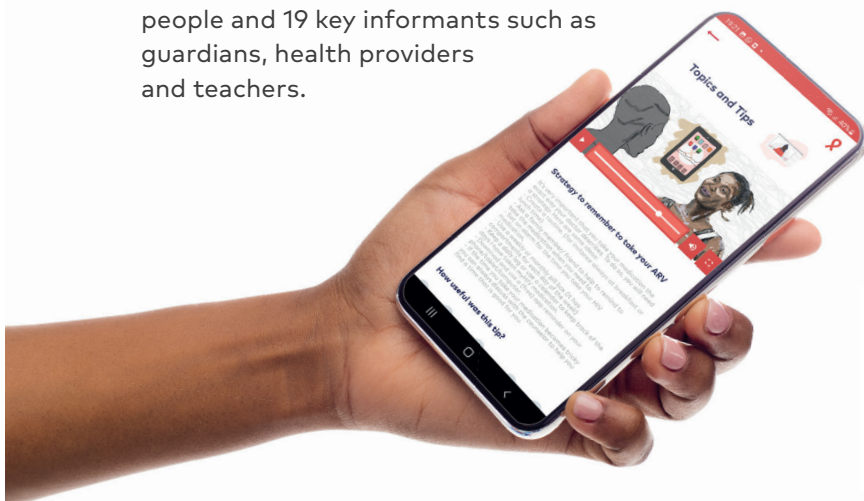
How it started

In 2016, around 5,000 new HIV infections in Malawi occurred among young people aged 10-19 years, accounting for about 15% of new HIV infections in Malawi. Young people living with HIV face greater risks of dropping out of care and stopping treatment compared to adults.

Community health volunteers in Chikwawa and Mangochi districts voiced concerns of poor treatment adherence among young people. In response, the Coalition of Women Living with HIV and AIDS (COWLHA) in Malawi conducted a study in 2018 to understand factors influencing treatment adherence. This was done through focus group discussions and interviews with 225 young people and 19 key informants such as guardians, health providers and teachers.

The study found the following themes to influence treatment adherence among young people living with HIV:

- **Mental health:** feelings of self-worth, attitudes and acceptance of their HIV status, motivations to live healthy and motivations driven by life aspirations or goals.
- **Supportive environment:** perceived level of support from family and friends.
- **Stigma and discrimination:** perceived level of stigma and discrimination in the community.
- **Treatment literacy:** knowledge of treatment regimen, confidence in adhering to treatment, access to youth-friendly health services and treatment concerns such as side effects and strategies of pill-taking.



What is the Thandizo approach?

Thandizo means 'support' in Chichewa language. Built on COWLHA's study findings, the Thandizo approach is a combination of support groups and the Thandizo mobile app, jointly developed by Aidsfonds and COWLHA.

Mobile app

The Thandizo mobile app is a risk-assessment tool for community health volunteers to support young people. It identifies risks for interruption of HIV treatment and provides information, advice and referrals to health services. During the development phase, young people with HIV identified community health volunteers to be trustworthy and knowledgeable. Therefore, the app was designed to facilitate sessions held by community health volunteers.

Individual consultations

During individual consultations, a community health volunteer and a young person living with HIV use the app together and choose topics of discussion such as treatment and health facilities, social support and personal experiences. After the young person completes a questionnaire, they receive a score indicating how well they are doing in the topics. The community health volunteer can use this information to identify risk areas for the young person's non-adherence. The app also provides personalized tips on how to improve health and

adherence through animation videos and short texts with graphics. Based on the young person's concerns or risks, the community health volunteer can also use the app to make referrals to appropriate services.

Group sessions

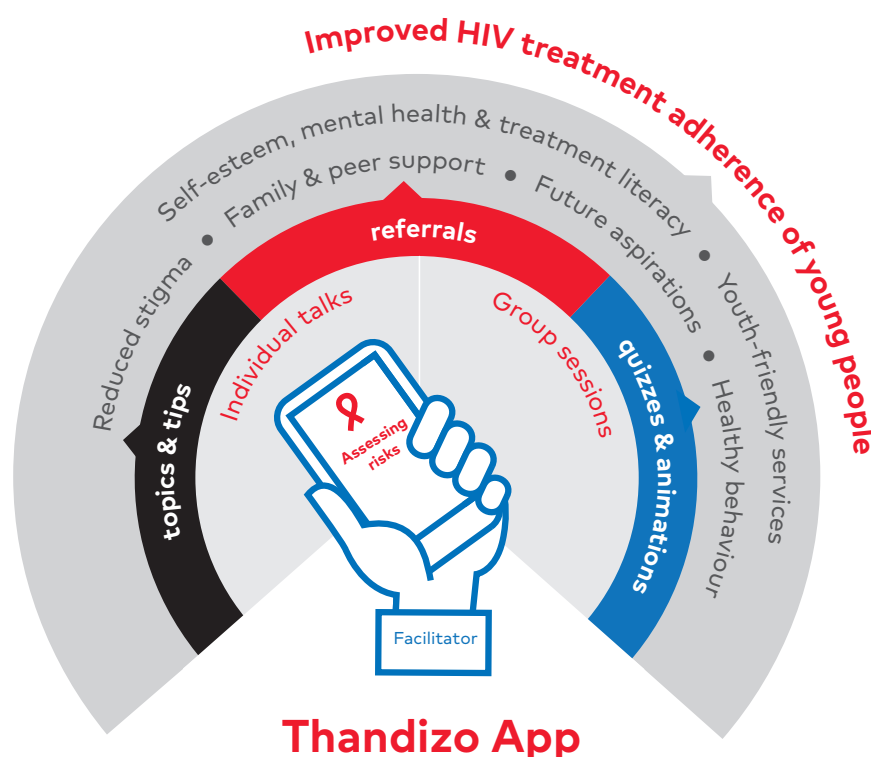
The app provides materials for community health volunteers to use in support groups with young people living with HIV. Discussion topics and animation videos aim to facilitate group discussions on topics such as stigma and discrimination, community knowledge and gender norms. Each topic comes with questionnaires that can be completed as a group, which will help community health volunteers identify the need for future interventions. The app also provides tips and advice based on the group's needs through animation videos and short texts with graphics.

Quizzes

Individuals and groups can use the quiz section to correct misconceptions of HIV and improve their knowledge on positive living and the mechanisms, effects and treatments of HIV.

Data collection

The app collects anonymous data of responses, which aims to support COWLHA, health facilities and community health volunteers to improve their services and interventions and adapt them based on the needs of young people.



How has Thandizo supported users?

The Thandizo approach has been piloted from 2020 to 2021 and evaluated by an independent researcher to investigate the effectiveness of the app and support groups. During this period, the app has been used by 40 community health volunteers in Mangochi and Chikwawa districts, reaching 4,767 young people.

The Thandizo approach proved to be successful in improving HIV treatment adherence. Data results showed decreased numbers of young people who stopped treatment and increased members in support groups. Community health volunteers reported feeling supported and witnessed improvements among young people. Young people reported improvements in knowledge, mental health and confidence to continue adhering to treatment.



Sharing experiences at a support group meeting

"Before we started learning through the Thandizo App, each one of us thought being on ART, we would never be able to fall in love again... Through the interactions that we have with the mentor and amongst ourselves, such mindset is a thing of the past. Everyone is becoming more and more open, a thing that has also helped us to attract more fellow youths to join the support group."

– Young person aged 24 - Chikwawa district

Quantitative health-facility data analysis

According to quantitative health-facility data gathered by COWLHA, the approach proved to be successful in:

- Decreasing treatment defaulters
- Increasing numbers of young people being brought back into care

	Mangochi 4 health facilities		Chikwawa 5 health facilities	
Number of young people:	2019	2021	2019	2021
who started treatment	149	114	332	298
who stopped treatment	384	87	94	9
brought back in care	6 (2%)	81 (93%)	19 (20%)	8 (89%)

The data compares results from the baseline year (2019) and the evaluation year (2021).

- Increasing referrals made to health facilities and support groups. The decreased referrals made to health facilities in Chikwawa was explained as a result of reduced number of young people who stopped treatment.

	Mangochi		Chikwawa	
Referrals to:	2020	2021	2020	2021
health facilities	75	207	384	186
support group	223	221	287	374

- Increasing membership of young people in support groups due to referrals. This was suggested to be partly caused by strengthened relationships between community health volunteers and healthcare workers.

	Mangochi 11 support groups		Chikwawa 25 support groups	
	2019	2021	2019	2021
support group members	169	451	226	979



Results from focus group discussions and interviews

According to focus group discussions and interviews, the approach proved to be successful in:

- **Increasing self-efficacy.** Young people reported increased knowledge and skills through animation videos and quizzes and increased confidence to get back on treatment.
- **Improving mental health.** Young people reported that the animation videos corrected misconceptions surrounding HIV which contributed to increased self-worth and decreased denial. For example, many girls learned that people living with HIV can get married. Referrals to get psychosocial support taught young people how to deal with anxieties.
- **Seeking support from friends and family.** Young people reported that the approach encouraged them to disclose their HIV status to family and friends.
- **Teaching how to deal with stigma and discrimination.** Young people reported increased understanding of the effects of stigma and discrimination and how to deal with them.
- **Improving treatment knowledge and skills.** Young people and community health volunteers found the approach to be effective in reminding young people the importance of taking ARVs properly and at the right time.

Methodology

COWLHA gathered data on the number of referrals made, of young people who stopped treatment and support group members. The external researcher held 10 focus group discussions and 13 interviews. 8 focus groups consisted of young people randomly selected from support groups and 2 of community health volunteers. 8 interviews were conducted among young people and 5 with key informants such as health workers, parents and COWLHA representatives. A total of 66 people participated in this evaluation.

For more information about Thandizo, visit:
aidsfonds.org/thandizo or reach out via
contact@aidsfonds.nl

Future of the Thandizo approach

Improvements to be made

Based on most significant recommendations from the evaluation, Aidsfonds and COWLHA aim to improve Thandizo by:

- Shifting towards a system that is centered around young people with HIV themselves. By for example a pilot in which peer educators and youth support group leaders administer the Thandizo app. Or establishing partnerships between peer educators and community health volunteers, in which they learn from and coach each other;
- Engaging with relevant stakeholders to incorporate solutions to issues that hinder treatment adherence, such as access to nutrition and economic empowerment;
- Refresher training for community health volunteers and support group leaders to update them on new developments regarding HIV, equip them with more knowledge on HIV, to clarify their roles and to build synergy in their work.

Adoption and scale up

The success of Thandizo allows Aidsfonds and COWLHA to explore options for scaling up the approach to support more young people living with HIV in other districts and countries. We are seeking to:

- Share evidence and learnings from the Thandizo approach to encourage further uptake and scale. Aidsfonds and COWLHA can provide technical guidance and training on implementation of Thandizo;
- Explore opportunities with stakeholders and partners to gather funding for scaling up the approach.

