

# Supporting adherence

## Young people's experiences of HIV treatment

HIV treatment is very effective. If young people living with HIV are diagnosed early and take their treatment, they can lead long healthy lives.

It can be difficult to stay on treatment without support. Young people need friends, family and health workers to help them.

Stigma and discrimination make it harder for young people living with HIV to access treatment. We need new initiatives to combat stigma and provide clear, honest information about HIV.



READY to Talk BRIEFING

## About READY

READY is a movement of youth-led and youth-serving organisations implementing initiatives designed to build resilient and empowered adolescents and young people. We know this is vital because AIDS is the second largest cause of death of adolescents globally, and the first in Africa.

Young people all over the world are joining the READY movement to demand their right to a healthy life whatever their circumstances, sexual orientation, gender identity or expression. Young people helped create the READY movement and they remain at its core.

The READY movement is led by the Global Network of Young People Living with HIV (Y+), with support from Frontline AIDS and its partners.

**READY +** is a programme working with, and for, adolescents and young people living with HIV in four southern African countries. At the beginning of the programme, young leaders went out into their communities and spoke to their peers to understand the experiences, perspectives and needs of adolescents and young people living with HIV as well as the communities around them. The key findings from these conversations are shared through three briefing papers. They focus on disclosure, sexual and reproductive health service provision and, in this brief, treatment adherence.

## READY Movement

[www.yplusnetwork.org/ready-movement/](http://www.yplusnetwork.org/ready-movement/)

 [fb.me/READYMovement](https://fb.me/READYMovement)

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### Front cover photos:

Peer supporters from Tanzania and eSwatini (from left to right):

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## Acknowledgments

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## About Frontline AIDS

Frontline AIDS wants a future free from AIDS for everyone, everywhere. Around the world, millions of people are denied HIV prevention, testing, treatment and care simply because of who they are and where they live. As a result, 1.7 million people were infected with HIV in 2018 and 770,000 died of AIDS-related illness. Together with partners on the frontline, we work to break down the social, political and legal barriers that marginalised people face, and innovate to create a future free from AIDS.

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## Research methodology

The content of this issue brief derives from a community documentation process conducted by READY+ partners during 2017 and 2018, and a post-analysis reflection on the core themes conducted in July 2019 with READY+ youth focal points from Y+.

A total of 36 focus groups were held in nine predominantly urban locations in eSwatini, Mozambique and Zimbabwe. Half of the focus groups were conducted among young people in their diversity, including adolescents aged 10-14, young LGBT people, young sex workers aged between 18-25, and community adherence treatment supporters (CATS). The remaining focus groups were among healthcare workers, parents and caregivers. A total of 300 people, many of whom are living with HIV, took part.

Two capacity-building workshops were held in each country. These trained a total of 116 young people aged 18-25 (mainly young women) in research methods, focus group facilitation and data collection. Each focus group was organised and facilitated by young people trained during these workshops.



...taking medication every day can be challenging.  
© Gemma Taylor for Frontline AIDS.

## Young people and HIV

Whether they are born with HIV or contract the virus later, all young people living with HIV need to take medication to control the virus and stay healthy. If they are diagnosed before their immune system has been too damaged and take the treatment they are prescribed, they can lead long, healthy lives. It is particularly important to take the treatment as instructed because missing doses allows HIV to increase and become drug resistant. But taking medication, especially every day, can be challenging. In addition, young people's ability to remain on treatment is often hampered by the misinformation, myths and stigma surrounding HIV and other people's attitudes. They may also lack the practical support they need, whether that is to attend hospital appointments or remember to take medication. Other barriers, often caused by poverty, may also stand in their way, such as a lack of food or money for transport.

Yet young people are broadly aware of the importance of HIV treatment and can be braver about disclosing their status, and more focused on taking medication, than older people. This is demonstrated by the way in which young people living with HIV were prepared to take part in the focus groups, where they spoke openly about what helps when it comes to adhering to treatment and the challenges they face.

“It's important for the parents to disclose the status to them ..... so that they (are) able to continue taking the medication without defaulting.

Focus group participant

“One of the good things [about being young] is that people tend to be more resilient. My own daughter ... is more confident and doesn't need anyone to tell her to take her medication.

Focus group participant



◀ Felicitus Ngubo trains young peer supporters to improve outcomes across the HIV care cascade in eSwatini, Mozambique, Tanzania and Zimbabwe. © Frontline AIDS.

# Talking to young people about HIV

Young people want to understand the full facts about HIV as a virus as well as their treatment, their life expectancy and many aspects relating to living with HIV. In the focus group discussions they shared their unanswered questions about HIV, which included: "I want to know about the pills that we take ... for how long will they work?" "I want to know, how do you prevent HIV?" Young people said they hear people around them speaking about HIV and need guidance to know what to believe: "I want to know the types of HIVs that we have ... because I've heard also that there's another type of HIV that can be cured and there [are] some that cannot be cured."

Some young people may be unaware of their status, despite having been diagnosed. Carers or parents may keep their child's HIV status a secret to try to protect them from stigma and discrimination and to stop them from worrying [see our disclosure brief]. Young people may be given HIV medication but will be told the pills are vitamins or to prevent headaches or some other illness. One of the CATS said they had seen the impact of this: "Guardians are not disclosing their status to their children, and that becomes difficult for the children to take their medication." As children grow up and begin to take on more responsibility for their own healthcare they are less likely to continue their treatment if they do not know why they are taking it. Some parents disagreed with keeping a young person's positive status a secret: "It's important for the parents to disclose the status to them, and to tell them how they got it, so that they be able to continue taking the medication without defaulting."



Community adolescent treatment supporters (CATS) are young people who work between the health facilities and homes of children, adolescents and young people living with HIV to improve outcomes across the HIV care cascade. © Jenny Berg for Frontline AIDS.



## Secrecy surrounding treatment

One consistent message came out of all the focus group discussions: young people living with HIV are worried that other people will discover their HIV status and they will suffer stigma, discrimination and mistreatment as a result [see our disclosure brief]. Because of this, young people who are HIV positive often try hard to hide their HIV status and this can make it difficult for them to get the care and treatment they need. For example, some young people try to avoid visiting their local health facilities. One CAT explained: "Sometimes they are afraid that they could see someone that they know at the clinic. He will tell the community about their status. Going around gossiping about them... about their status."

Instead, many young people choose to visit clinics that are further away from their home where they will not be recognised. But having to regularly embark on long, expensive journeys can make it hard to stay on treatment. It also makes it hard for healthcare workers to support young people to adhere to treatment as they may struggle to maintain contact: "A challenge that we face as healthcare workers is actually keeping a follow-up on some of the young people ... because they live far they cannot come again, so it is quite difficult ..."

Young people in the focus groups described different methods for taking their medication in secret. One of the CATS explained that some young people took their pills out of the bottles so they would not rattle and make a noise when they were taking them. Another young person spoke about struggling to find an opportunity to take their tablets at home: "Then it is time for me to take the tablets. No one knows that I am HIV positive okay, then I will not have a chance to go and take my tablets in time." One health worker explained that, when young people felt they had no way of keeping their medication secret at home, "they end up asking to leave their medications at the healthcare facility".

It is clear that there is still considerable misinformation about HIV. Not only is it important that the myths are dispelled, it is also important for young people living with HIV, their families, friends and communities to be able to access up-to-date, accurate and appropriate information.

“ Sometimes they are afraid that they could see someone that they know at the clinic (who) will tell the community about their status. ”

Focus group participant



## Economic barriers

Many people in the communities where our focus group discussions took place are struggling financially. Economic hardship can impact on the ability of young people living with HIV to take their treatment. In each of the three countries, people spoke about a lack of food. A parent in Zimbabwe explained: "As a community we are failing to give these young people that are living with HIV a balanced diet, because of economic hardships ... and as a result they are facing again more health challenges." A parent in eSwatini said: "The food is not enough and we need to take the medication with food and that becomes a problem." One of the CATS in Zimbabwe said: "I just wish ... if there are some social welfare [services] that can be able to help children who are living with HIV ... financially... because some, they are facing challenges, they are not getting any money ... even to feed themselves."

Although most HIV-specific treatment is free there are many other costs attached to accessing treatment and care for young people living with HIV. Some families are unable to meet the costs of travelling to health facilities or to buy medication for other related illnesses. One parent said: "The guardians don't have the money to constantly visit the health facility since they have to pay for the services."

“As a community we are failing to give these young people that are living with HIV a balanced diet because of economic hardships, and as a result they are facing again more health challenges.”

Focus group participant



▶ In Tanzania, peer supporters use the soldier game to educate young people living with HIV /AIDS about how antiretrovirals work in the body. © Peter Caton.

## Family support

Young people are surrounded by individuals who have the potential to support them to access the treatment and care they need. Their help can make all the difference, as this healthcare worker explained: “We see good adherence if they have treatment support.” Conversely, young people described struggling to adhere to treatment due to a lack of support: “If you don’t have family support you end up abandoning your treatment. Because you are scared how people will look at you and that ends up prejudicing your own health.” Health workers said they found that young people who lacked a support network were more likely to miss their appointments or not take their medication: “Young people don’t trust other people to disclose to ... they don’t even disclose the date when they must come to hospital. What we face is young people that can miss to come to hospital today because they were at school. If they have disclosed, the trusted person would have come here to fetch the pills because the most important thing is to take these pill[s].” If young people stop taking their medication their health can deteriorate quite quickly: “Most of these adolescents, they end up defaulting their medication because at times they feel tired ... and if they are on second line, it gets more difficult because you have more pills to take, and it’s not easy for them.”

For many young people, a parent or other close family member is their main source of support. One young man described turning to his mother for help: “I can tell her I am going to collect my pills and to support groups. She gives me the money to come here and she reminds me to take my medication in time and if I fall sick she asks whether I am taking my medication or not.” Another young person explained: “The pills make me feel ok, I take them everyday and sometimes my mother reminds me and sometimes I use my phone alarm.” In a different focus group a parent described how they can help: “The [young] person is actually safer when they are with their parents who know about their status. The reason being is that they actually help them to ... take their medications.”

“We see good adherence if they have treatment support.”  
Focus group participant



Young peer supporters are on the frontline of keeping other young people healthy. © Peter Caton.



## Other sources of help

Health workers can also support young people with their treatment. Many focus group participants had positive experiences at their clinics and felt able to turn to doctors and nurses for information and support. One health worker said: "Sometime their health providers not only must be a health provider but must take a place of father or mother, so they can help this young person." However, some young people spoke about being mistreated by health workers, who they felt discriminated against them because they are living with HIV: "The nurses, doctors and people who attend [to] us in the hospital, as they know that they are not HIV positive, they take us down and attend [to] us in a bad manner."

It is often a health worker who first tells a young person their HIV positive status. At this point, and throughout their care, health workers have an important role to play in providing psychosocial support. However, health workers may lack the time they need to talk to young people properly and answer their questions. As one health worker explained: "What normally happens is the nurse will give an office for a while but does not allow for enough time with the patient to give information properly."

In the areas where our focus groups were held, CATS play a vital role in helping young people living with HIV adhere to treatment. During home and clinic visits, CATS provide information, counselling and support to other young people living with HIV and encourage them to stay on treatment. One of the CATS gave an example of the impact they can have: "There was a child who defaulted for about eight months, just because the caregiver said she was 'healed' ... so the child stopped taking the medication and she deteriorated very much. And we helped that child get back on treatment. She's now on treatment and she's recovering bit by bit ... it was a tough case."

Teachers are another part of a young person's potential support network. A sympathetic teacher can understand the need for absenteeism or look out for signs of a pupil being unwell in class. One parent explained why they felt a teacher should know a child's HIV status: "It is important so that they can also support and assist the child ... for example, these ARVS [antiretrovirals] sometimes they make you get dizzy, and maybe the child will be sleeping in class, so the teachers will understand that the child is on ARVs."

“The (young) person is actually safer when they are with ..... parents who know about their status. The reason being is that they actually help them to ... take their medications.”

Focus group participant



## Youth-friendly treatment services

Young people living with HIV are trying to balance many different aspects of their lives alongside their HIV treatment and care, be it school, family responsibilities, relationships or work. Systems or services that are flexible enough to adapt to these differing needs can help young people adhere to treatment (see our brief on sexual and reproductive health services). For example, one parent suggested a way to help young people who prefer to avoid their local health facilities: "If you could even conduct home visits and come and talk to these children because for some, even as old as 18 years, they do not even want to go and collect their own meds at the hospital ... if you do not go and collect the meds for them they will even default, because they don't want to be seen and they don't want to be known that they are HIV positive." Some people suggested developing a system that coordinates timings between schools and hospitals so young people do not have to miss lessons: "We must change the way we treat them; people that go to school in the morning must come in the afternoon and those who go to school in afternoon must come in the morning."

Many focus group participants spoke about the role of support groups: "The doctor put my kid at the support group and now she has all the information and doesn't have a problem. Now she takes the medication on her own and she doesn't forget and is doing fine." As well as providing information, the support groups offer young people a chance to share their experiences with their peers. One young person described the group they attend in eSwatini: "We have a group; a group of children who are also taking pills. We talk about the importance of taking pills, our lives, how we should live to stay healthy."

Counselling services are particularly important but must be adapted depending on the age of the young person. Some health workers spoke about the counselling they offer: "When they come for results and know they are HIV positive it is difficult for them to accept that information, so when we counsel them it is easier for them to do treatment and accept the information." They also described the tools they use to explain the importance of adherence, especially to younger age groups: "I talked to the young girl and I explained – they have a card that explains about ... it is like a game that shows what kind of virus they have – so I helped her play with the card. I convinced the girl that what is happening is that, she may feel alright that day, but as time goes by she will regret [not taking medication]. Because there will be a moment that she will see that there was a problem in the time that she kept hiding her pills."

“We must change the way we treat them; people that go to school in the morning must come in the afternoon and those who go to school in the afternoon must come in the morning.”

*Focus group participant*

“The doctor put my kid at the support group and now she has all the information and doesn't have a problem. Now she takes the medication on her own and she doesn't forget and is doing fine.”

*Focus group participant*

# Young people's recommendations

“Peer supporters are there to act as a pillar of strength to their peers by providing information, encouragement, support, counselling; instilling confidence through shared experiences in order to boost self-esteem.

*I've changed lives by sharing my story.* Shanine Mushonga,  
Differentiated Care Youth Ambassador and Youth Advocate of Africaid.

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## Governments

**1. Support bold new initiatives to eliminate stigma and discrimination.** We need to share strong, clear, positive information about living with HIV. Empower young people living with HIV to feel safe to share their HIV status with family, friends and their school.

**2. Address the structural barriers to treatment.** Ensure that young people and their families do not have to pay to reach the services they require. Where needed, provide nutritional support for families where a member is living with HIV.

**3. Invest in communities.** Provide resources for community-based organisations to continue, and expand, their work, including as educators, treatment supporters and counsellors. Provide funding for CATS, and other peer treatment supporter models that have been proven effective, to work both in health facilities and within communities.



## Implementers / health facilities

**4. Improve treatment literacy.** Ensure that young people have full information about their treatment and the importance of adherence, and address any myths or misinformation about HIV treatment.

**5. Ensure treatment clinics are youth-friendly.** Make sure that adolescents have options on how, when and where they receive support. Services should be flexible to take in to account different preferences and needs. Consider youth-only services, such as allocating one day each week when only young people can attend a clinic.

**6. Use mobile clinics.** Tailor the services provided by mobile clinics to the needs of adolescents and young people in all their diversities.



## Communities

**7. Support the families of young people living with HIV.** Educate and support parents and caregivers so they can disclose their child's HIV status to them (following WHO guidance) and support their child to remain on treatment.

**8. Strengthen psychosocial support for young people living with HIV.** Use peer supporters within the community, including CATS.

**9. Create safe spaces.** Make welcoming places where young people in general, and young people living with HIV, can gather and learn about HIV and treatment.





“Peer supporters are there to act as a pillar of strength to their peers by providing information, encouragement, support, counselling; instilling confidence through shared experiences in order to boost self-esteem. I’ve changed lives by sharing my story. Shanine Mushonga, Differentiated Care Youth Ambassador and Youth Advocate of Africaid.”



READY+ aims to advance sexual and reproductive health and rights (SRHR), psychological wellbeing, care and treatment with, by and for 30,000 adolescents and young people living with HIV in Mozambique, eSwatini, Tanzania and Zimbabwe. The programme is being implemented by an innovative and multi-disciplinary consortium of youth, SRHR, HIV and communication partners.

READY+ is one of a portfolio of projects being implemented under the READY programme. For more information, visit <https://frontlineaids.org/our-work-includes/ready/>



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