



RITSHIDZE

SAVING OUR LIVES



Session 3A Reasons for disengagement and re-engagement in HIV care

3.1 Recipient of care perspectives



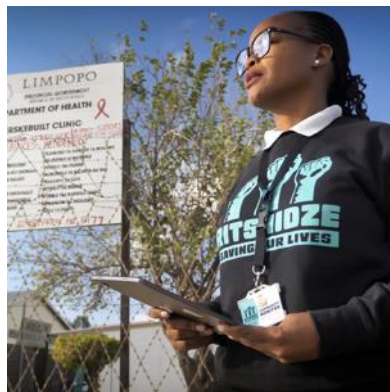
Background

Over the past decade, South Africa's HIV response has come a long way — from the dark days of AIDS denialism under then President Thabo Mbeki, to the establishment of the world's largest treatment programme.

However, this achievement only reflects half of the story. The full picture of South Africa also reveals that more than 2 million people living with HIV are still not on lifesaving HIV treatment — either never having known their HIV status, or more worryingly having started on treatment and then stopped.

South Africa's failure to make sufficient progress towards the UNAIDS scaled up 95-95-95 targets can be directly linked back to the crisis in our clinics.

Ritshidze was developed and designed in response to this crisis. It was built out of early models of monitoring that TAC had been doing since 2015. It gives communities the tools and techniques to monitor the quality of health services provided at clinics (including HIV and TB services, and services for members of key populations) and escalate challenges to duty bearers in order to advocate for change.





Who we are

Ritshidze is being implemented by organisations representing people living with HIV including the Treatment Action Campaign (TAC), the National Association of People Living with HIV (NAPWA), Positive Action Campaign, Positive Women's Network (PWN), and the South African Network of Religious Leaders Living with and affected by HIV/ AIDS (SANERELA+) — in alliance with long term comrades in the fight for quality healthcare at Health GAP, amfAR, and the O'Neill Institute.

Together, we are working towards improving the quality of HIV, TB, and other health services provided in the public health sector through Ritshidze which is being rolled out in hundreds of primary healthcare facilities across the country.



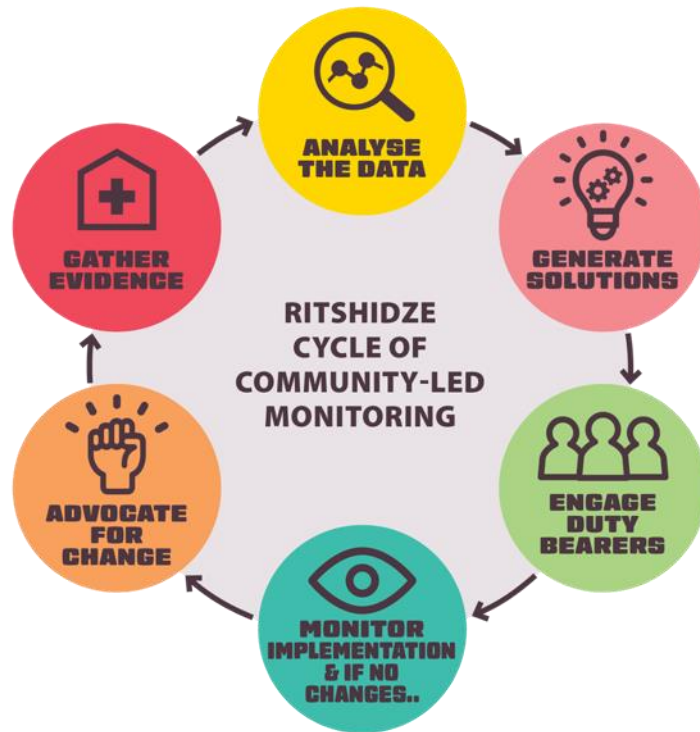
Ritshidze model

Ritshidze — one of the most extensive community- led monitoring systems in the world— was developed by networks of people living with HIV in South Africa to hold government and aid agencies to account to fix our broken public healthcare system.

Through Ritshidze, community members systematically collect data at local clinics that are analysed, and then used to generate solutions to problems that are put to decision-makers for action.

Community-led monitoring is a system of community-developed and community-owned data collection and monitoring at the site of service delivery, followed by development and implementation of advocacy solutions to respond to the evidence generated.

Through Ritshidze, communities carry out observational surveys, and talk to healthcare workers, public healthcare users, people living with HIV, and key populations. The evidence they collect will be used to advocate for changes with duty bearers such as the Department of Health and PEPFAR agencies/DSPs.



Ritshidze Indicators related to re-engagement with care

- + Data are collected through observations, as well as surveys with healthcare users (public healthcare users, people living with HIV, key populations) and healthcare providers (Facility Managers, pharmacists).
- + Additional quantitative and qualitative data is collected in the community specific to the quality of services for people who use drugs, sex workers, and LGBTQIA+ community members.

Staffing & Waiting Times
ART Collection & ARV Refills
ART Continuity





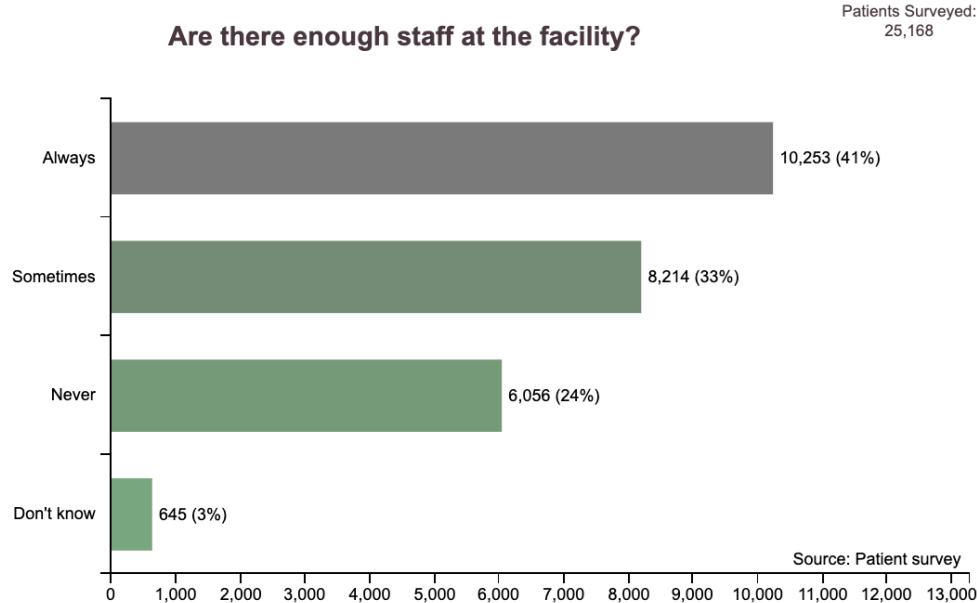
ABOUT THE DATA

Data in this report were collected between October & November 2024 (Q1 2025)

- + 471 facilities were assessed
- + 468 Facility Managers were surveyed
- + Observations took place at 470 facilities
- + 25,233 public healthcare users were surveyed
 - + 50% (12,740) identified as people living with HIV



Only 41% of public healthcare users say there are always enough staff

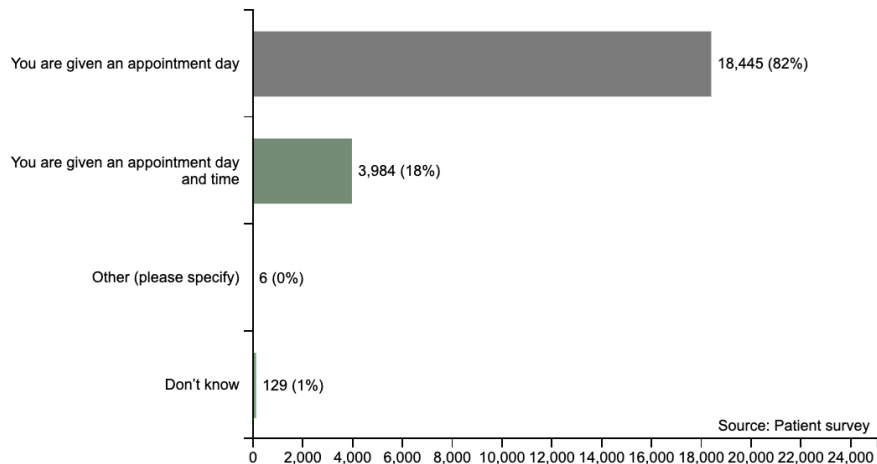


“They open the clinic at 8am. The nurses find us waiting in the morning and tell us they are short staffed and it will take time to help us” — a person living with HIV, Buffalo City, July 2024

Appointment systems

Which of the following best describes the appointment system?

Patients Surveyed:
22,564



“They used to give us a date and also a time for appointments, a long time ago. Now they are no longer doing that. They just give you a date and you go there at any time. It depends how many you are at that time” — a person living with HIV, Luyolo Clinic (Buffalo City), July 2024

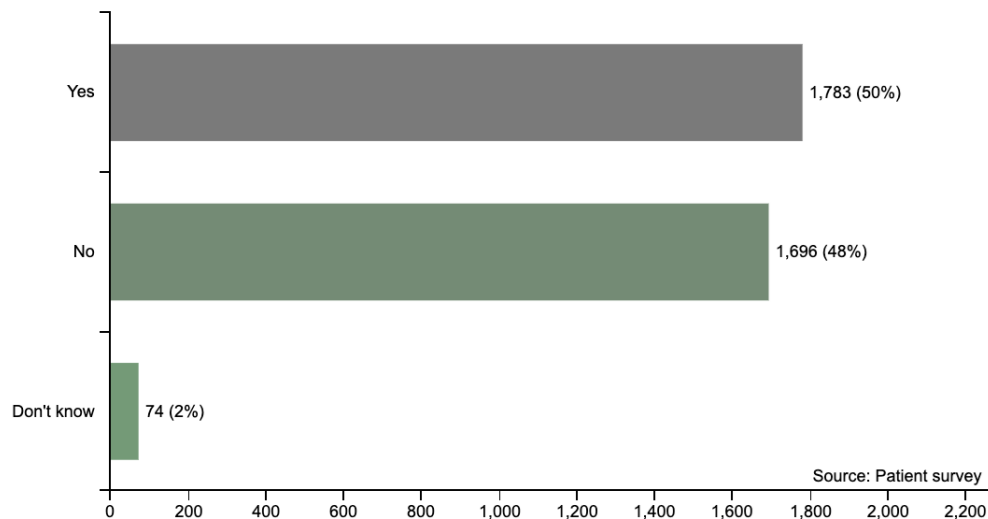


Pick-up points



Has the facility ever offered you an option to be in a facility pick-up point, external pick-up point, or adherence club?

Patients Surveyed:
3,553



48% said they have not been offered the option to use a facility/external pick-up point or adherence club

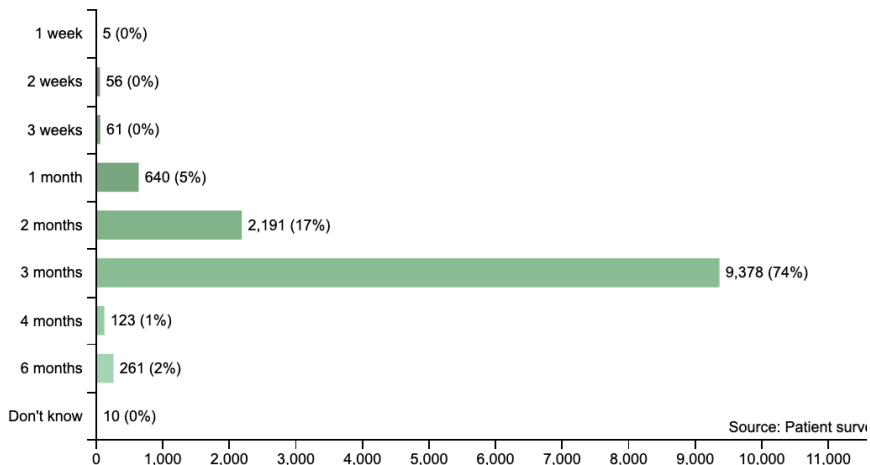
All eligible people living with HIV should be offered a range of pick-up point or club options, as per National ART Guidelines

ARV refill length



Length of HIV medicine refill

Patients Surve
12,725



"I finished my treatment yesterday and I have no more ARV pills left until my appointment date on 24 June. I am concerned about my viral load which could significantly rise. I am worried that I might even lose weight. I assume that there was a mistake when they were packing the medication. When I went to pick up my medication this month I noticed that there were fewer pills than before. I am a farm worker and my employer will not give me time off to go to the clinic" — a person living with HIV, Albert Luthuli Clinic (Lejweleputswa), June 2024

"I'm getting a 2 month ART refill but I would like to be given at least 3 months. It will help me as I have commitments. It will also save me time. You'll find that you have something to do yet you have to go to the clinic. I would be very happy if I could collect for longer periods at least 3 months, 4 months or 6 months" — a person living with HIV (Lejweleputswa), June 2024

"Sometimes the clinic will not have ARVs or they will give you one container of medication saying it lasts 2 months. The medication they give you finishes before time and it becomes a problem when you have to go back to the clinic. You will have to wait until they have the medication, but at that time you're not taking anything. I went there last month and I was given a 2 month supply. I would like to receive a 3 or 6 month supply. The change I want to see is better treatment for all patients and to be given enough medication" — a person living with HIV, Intabazwe Clinic (Thabo Mofutsanyana), June 2024

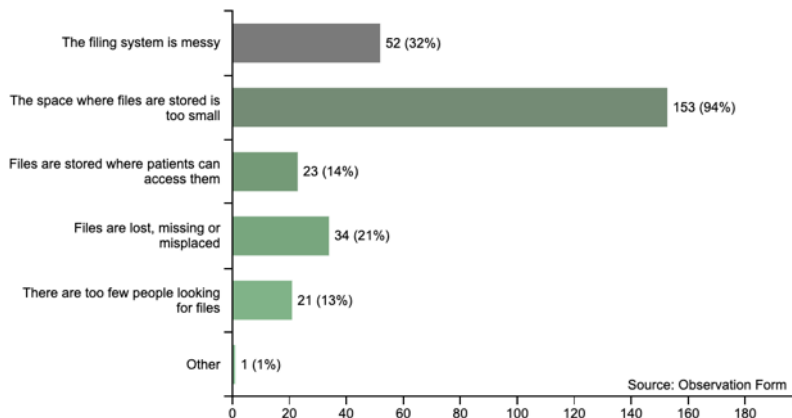
"They give me a 1 month supply of ARVs. I would like to receive a 6 month supply of ARVs" — a person who uses drugs living with HIV, Intabazwe Clinic (Thabo Mofutsanyana), June 2024

74% of PLHIV surveyed reported getting a 3 month ART refill.

Filing systems

What is in bad condition? Please select all that apply:

Observations
Completed: 162



Filing systems observed to be in a **bad condition in 35%** of sites monitored. **29% of people** who said waiting times were long blamed messy filing systems, it taking too long to find files, or lost files

Welcoming services



“If you miss your appointment you will be sent home. I went to the clinic for five months without being helped. I last went in February and gave up. I arrived early and was told I will be attended to last. I did not have any medication. The staff give us attitude and they don’t speak to us nicely. We get punished for missing dates. If you miss a date it can take the whole week without being helped. Even lodging complaints does not help, the problem persists”
— a person living with HIV, Rearabetswe Clinic (Thabo Mofutsanyana), June 2024

“I had gone to visit relatives for a while and went to the clinic to get my treatment on my return. They refused to give me the treatment and gave me another date to return on. I requested that they at least provide me with ARVs to take until the appointment date, as I had run out, but they refused. I was devastated by the treatment I got” — a person living with HIV, Intabazwe Clinic (Thabo Mofutsanyana), June 2024

“My stress is the clinic, you will arrive at 8am and leave at 3pm. We need to rest because we are working at night. When you arrive at 3pm they shout at you, telling you that you were not working yesterday. I don’t know if perhaps they keep tabs on us, if we are at work or not. When I send someone to collect my medication, they refuse to give them medication. They want me to collect medication even if I’m not due to take blood. When I return the following day and go to the clinic, they will shout at me for not coming on my appointment date” — a sex worker living with HIV (Lejweleputswa), June 2024

“Missing an appointment means waiting aside unattended even if you arrived at 6am, and being forced to take adherence classes. You’ll be taken aside and told to wait until they’ve finished with other patients, since you came in on the wrong appointment day. What we face at the clinic is painful. Even elderly people are shouted at and addressed rudely” — a person living with HIV, Flagstaff Clinic (OR Tambo), July 2024

“When I skip my appointment date, I am sent to the back of the queue. This makes me lose interest in this clinic. I defaulted because I was ordered to come on the following day repeatedly” — a person living with HIV, Buffalo City, July 2024



“I lost my clinic card but knew my return date for my ARVs. A nurse in the consultation room called me a “defaulter”, shouting at me while the door was open. Some of the patients and clinical staff were moving around and they could hear what was going on. She also chased me and said “I don’t have time for defaulters, there are serious people that seek my help”. As she said this she was standing up and telling me to sit outside while she helps serious people first and I was going to be last. I was so sad, felt humiliated and disrespected because I made every effort to visit the clinic early so that I could return to work to provide food at home” — Gompo Clinic (Buffalo City), interview in March 2023



Refused access without a transfer letter

245 people interviewed by Ritshidze in the last quarter reported having been denied access to services for not having a transfer letter.

It is important to note that Ritshidze interviews take place at the facility, therefore people who have already disengaged from care due to challenges accessing a transfer letter would not be at the facility to interview.





East London, 19 September 2023 — “I asked for ARVs and explained why I don’t have a transfer letter. The clinic made it difficult... I spent the whole year without treatment.”

For some people who move to a new place or relocate for work, getting access to lifesaving ARVs becomes a challenge. In the last year, a staggering 503 people interviewed in the Eastern Cape had been denied services because they did not have a transfer letter — something that is not required by ART guidelines to start or restart your ARVs*.

One community member explained: *“I have not taken my treatment in a few months because the facility requires a transfer letter. I suggested that they test and reinitiate me... but they said that would be difficult. I gave up and stopped trying.”* Another told us that he had not gotten treatment for eight months because the clinic *“refused to email the transfer letter”*.

Refused access without an ID

396 people interviewed by Ritshidze in the last quarter reported having been denied access to services for not having an identity document.

Again, it is important to note that Ritshidze interviews take place at the facility, therefore people who have already disengaged from care due to being refused services for not having an ID would not be at the facility to interview.



Lessons for other CLM programmes

- + CLM has to be regular — it is not a one-off activity.
- + CLM takes significant, well trained staff — as any other activity worth doing.
- + Engagement and advocacy component are critical to making it work. Detailed data helps uncover specific problems that cannot be dismissed as just anecdotes.

“It is communities who know what they need. It is communities who must tell those who pay for services what they want. Everywhere I go I see communities treated as though they should be grateful, not as people with rights. But I see you saying these are our rights. I thank the people who have put this project out here. This is just the beginning.” — Winnie Byanyima, UNAIDS



Lessons for health systems to improve re-engagement with care

- Experience on return is important
 - We need to stop punitive behaviour at return (shouting, being sent to the back of the queue, etc.).
- Improving health system quality with improve outcomes
 - What is the negative impact of poor filing systems on outcomes?
- Recipients of care should be provided with options for treatment refills