

MEMORANDUM

6 month ARV refills now!

1 December 2024

As we mark World AIDS Day, today in South Africa around 2 million people living with HIV are still not on lifesaving ARVs — some people not knowing their HIV status, others knowing their HIV status but not having started treatment, and worryingly many many people having started on treatment and then stopped. Why? Because our HIV response is being undermined by the dysfunction in our health system.

Our clinics are still in crisis.

We leave home in the early hours of the morning, only to wait all day to be seen. Our files take hours to find or go missing completely. For those who are late for their appointment date, when we return to the clinic we are shouted at and sent to the back of the queue to wait all day as punishment. Often staff are openly hostile to people from the LGBTQIA+ community, people who use drugs, and sex workers — and if you don't have an ID when you go to collect your treatment or a transfer letter when you move from one clinic to another, or if you are a member of a key population you might be refused ARVs and sent away.

Some people living with HIV continue to suffer these daily indignities. Yet frustration and fear of this unwelcoming environment means some people stop going, or are scared to go back to the clinic after they are late for or miss an appointment, even though often this is for unavoidable reasons. **One thing is clear: No-one wants to go to the clinic more often than necessary, especially just to pick up your medicines.**

The Treatment Action Campaign (TAC) is marching today because there is hope. There are simple solutions to improve this situation. One is for people who are collecting ARVs to get a longer supply of medication.

A longer supply of ARVs would mean fewer trips back to the clinic. It would make it easier to stay on treatment by reducing the cost of getting to the clinic and the hours spent waiting there four to six times every year. Importantly it would also reduce congestion and overall waiting times for everyone using the clinic — and reduce the burden on already overstretched healthcare workers. There is strong evidence that shows that longer ARV

supplies help people to stay on treatment. In the context of South Africa's treatment retention crisis, this is essential.

We are marching today because South Africa's national guidelines allow for people to get a 6 month supply of ARVs from their clinics. The World Health Organisation (WHO) recommends that preferably people doing well on treatment should be getting a 6 month supply of ARVs. This would mean going to your clinic just twice a year for clinical review, rescript, and collecting your next 6 month supply of pills. It's now December 2024 and while more people are getting a 3 month supply, there is no public implementation plan in place for getting people a 6 month supply. This is an extremely simple intervention with big gains for people living with HIV, and the public health system more broadly. **More than 6 million people across Africa are already getting a 6 month supply with good retention and viral suppression outcomes, so why not here in South Africa where we have the biggest HIV burden in the world?**

We are marching today because another simple solution exists to improve retention — for people living with HIV to collect our medicines closer to where we live or work. Out of facility pick-up points, which already exist in South Africa, can make ARV collection easier and quicker, but 18,860 people — 38% of those surveyed by Ritshidze over the last year still wanted to collect their ARVs closer to home. We urgently need many more external pick-up points, closer to where people live and work, including in rural and peri-urban areas. To make this happen we need the department to make it simpler and more fairly funded for more community based organisations to register and run external pick-up points. The funding model must be geared towards reimbursing operational costs when community based organisations are only providing treatment collection services to a small number of people. R10 per person is not enough! This would not only provide easier access to external pick-up points for people living with HIV, but allow community-based organisations to participate in supporting people to stay on treatment and improve retention in their communities. Early childhood development centres are located throughout South Africa's different geographies. They are already registered as service providers. They could provide a possible solution to providing treatment to people closer to their homes and workplaces.

We are marching today because not only do we need to make ARV collection easier, we must immediately stop the ingrained culture of punishing those who are late for appointments. Healthcare workers must recognise that as people living with HIV we might be late for or miss appointments, and may even miss taking some pills. **That is normal!** The response to this must be to immediately give people their ARVs when they return, to

minimise any treatment interruption as much as possible. This ensures that a missed appointment does not become a prolonged treatment interruption which can increase illness, hospitalisation, and death — as well as onward transmission.

Yet often when we return to the clinic we are punished. Ritshidze data shows that 2,664 people who had been late for or missed appointments in the last year said staff shouted at them (12% in total) — and 3,353 people (15% in total) were sent to the back of the queue being forced to wait the whole day as a punishment. Alarming, some people even report health workers denying them ARVs following a late or missed appointment. **Yet national guidelines say that no punitive actions should be taken. These guidelines must be implemented properly.**

Importantly national guidelines also state very clearly that until 28 days have passed you have not even missed an appointment. The guidelines clearly state you should be able to collect your pre-packed ARVs at your pick-up point with no change to your service delivery. We fought hard for this flexibility. This flexibility is not being implemented and pre-packed ARVs continue being returned from pick-up points to clinics or CCMDD after 7 days!

We are marching today because changing between clinics can also turn into a nightmare. Over the last year 1,343 people told Ritshidze that they or someone they knew had been denied services without a transfer letter — something that is not required by ART guidelines to start or restart your ARVs. The reality is that people often relocate temporarily or permanently and people do not have the money or time to go back to their original clinic to get a transfer letter, often hundreds of kilometres away. At times, clinics even actively withhold them. While transfer letters are important, they must not be used as a barrier to helping people collect ARVs. We continue to be alarmed that in today's world, healthcare workers are still having to rely on a physical transfer document to know that a person is taking ARVs in the public healthcare system. In addition migrants and those without IDs, and people who use drugs, sex workers, and LGBTQIA+ community members also reported to Ritshidze that they had been denied services in large numbers. This is a humiliating, painful, and unjust experience to go through — and a violation of the Constitutional right to health, equality, and human dignity. **While some people may suffer the indignity of trying to get services another time, others can be pushed out of care altogether.**

We are marching today because we simply cannot get everyone on HIV treatment when intolerable conditions remain at clinics, when guidelines are not implemented, or by denying people health services. We are marching today because the department

says it wants more than a million people to start or get back onto treatment by the end of 2025. But the truth is that treatment for all — and reaching the UNAIDS 95-95-95 targets — is impossible without making it easier for people to collect HIV treatment. This must include decongesting clinics by providing 6 month supply to people doing well on their treatment and 3 month supply for everyone else who is not sick. We are marching today because we have been calling for 6 month supply for many years, yet the department keeps asking us if people living with HIV really want it. As people living with HIV, we can tell you, we really want it! Hear us today.

We ask that you carefully hear and take to heart the demands we are giving you today. These are not nice-to-haves, they are lifesaving.

Demands:

1. The National Department of Health **must urgently finalise its planning and forecasting processes to ensure that all eligible people get a 6 month supply of ARVs if they want it.**
 - a. An implementation plan with timelines must be made publically available by 15 December 2024.
 - b. Roll out must start before the end of 2024.
 - c. At least 30% of people living with HIV must be receiving a 6 month supply by end June 2025.
2. The National Department of Health must **hold provincial and district health departments accountable to ensure that everyone else who does not want a 6 month supply and who is not sick gets a 3 month supply.** This includes ensuring that all facilities and clinicians know the guidelines related to 3 month supply (3MMD); actively encouraging and supporting accelerated implementation at all facility, sub-district, district, and provinces HIV programme meetings; and monitoring 3MMD coverage (how many people collected HIV treatment and the percentage who got 3MMD) and hold facilities that are underperforming accountable.
3. The National Department of Health and Treasury **must ensure that an additional 100 small community-based organisations including those in rural and peri-urban areas are registered, viably funded and are running external pick-up points by end June 2025.**

4. The National Department of Health **must implement the guidelines that support 28 day flexibility for the collection of ARV refills**. This means until 28 days have passed you have not missed an appointment, your pre-packed ARV supply will remain for collection at the same pick-up point and will not be returned to clinics or CCMDD.

5. The National Department of Health must hold **provincial and district health departments accountable to fix the other challenges in our clinics that make people stop taking their ARVs**. Clinics must be held accountable to immediately stop taking any punitive action if people are late for or miss appointments (including shouting at people, sending people to the back of the queue, or withholding ARVs). Clinics must also be held accountable to immediately stop denying people services and ARVs without transfer letters, IDs, or because they are an LGBTQIA+ community member, a sex worker, or use drugs.

We demand a written response by 1 January 2025 and a meeting to respond to our memorandum on or before 31 January 2025.

Signed (Deputy President):

Signed: _____

Signed (Treatment Action Campaign):

Signed: _____

Signed: _____

Date: _____

Date: _____

Signed (Minister of Health):

Date: _____