Community Perspectives on Re-Prioritizing the HIV Response

Sibongile Tshabalala
South Africa’s HIV response

+ South Africa has 7.8 million people living with HIV — yet remains dangerously off-track to meet 95-95-95 targets
+ Too many individuals are lost before they initiate ART + once PLHIV do initiate treatment, there are severe ART continuity problems.
+ Key populations face additional barriers accessing HIV prevention and treatment services.
+ According to UNAIDS’s 2021 data — 650000 people died during the year despite effective HIV treatment and tools to prevent, detect and treat opportunistic infections.
+ COVID-19 has worsened healthcare — in 2021 there was a decline in the overall number of visits to health facilities, less HIV + GeneXpert tests carried out.
+ Only 52% of children living with HIV have access to life saving medicines
+ The failure to make sufficient progress towards the 95-95-95 targets can be directly linked back to the crisis in our clinics in the province AND poor quality public healthcare services.

South Africa has the largest treatment programme in the world + poor quality services undermines not only the response in South Africa but across the continent.
Ending AIDS by 2030

+ Insufficient investment and action putting us in danger
+ Inequalities that drive pandemics - tech & stockouts
+ Treatment literacy: attaining U+U
+ Honouring pledge

Patient reports of medicine shortage(s)

- HIV medicine: 155 (13%)
- PrEP: 1 (0.01%)
- TB medicine: 6 (0.5%)
- Contraceptives: 387 (40%)
- Pregnancy Test: 101 (8.8%)
- Vaccines: 105 (9.2%)
- Bandages (or other stock): 63 (5.6%)
- Other medicines/medicines: 181 (16%)
- None of the above: 96 (8.6%)
- Don't know: 61 (5.4%)

Source: Patient survey
Community-led monitoring: a strategy to identify challenges in reaching 95-95-95 targets

+ Ritshidze was developed in response to this crisis by people living with HIV and activists. It aims to hold the South African government and aid agencies accountable to improve overall HIV and TB service delivery and to support getting to the 95-95-95 targets

+ We need to identify and address challenges that cause PLHIV to never start treatment or disengage from care by holding local, national, and international officials responsible for delivering quality services to our communities.

+ Ritshidze monitors over 400 clinics & community healthcare centres across 29 districts in 8 provinces in South Africa — and unites the entire PLHIV Sector in South Africa. It is one of the most extensive community-led monitoring efforts in the world.
Understaffed clinics mean healthcare workers are overburdened. This leads to longer waiting times, limited time to attend to patients, and at times, bad attitudes. These factors directly contribute to PLHIV starting and staying on treatment and can be linked to poor attainment of 95-95-95 targets. Provincial health teams should ensure that all vacancies are filled and address shortages of staff identified at site level.

Early mornings, feeling unsafe outside the clinic, and long waiting times cause people to dread clinic days or even stop going. All clinics should have functional filing systems to avoid extra delays/confusion and where possible extend facility opening hours (as per the NDoH circular from 5am to 7pm on Monday to Friday).

Unnecessary trips to the clinic just to collect an ARV refill adds both a burden on PLHIV and to the already overwhelmed clinic and healthcare worker staff. This inefficiency can also contribute to PLHIV disengaging from care. All clinics should retain government gazetted 12 month ART scripting + ARV refills should be extended to 3 to 6 month supply for all eligible PLHIV. In addition at least 60% of PLHIV should be decanted to External Pick Up Points closer to home, reducing the burden on clinics and PLHIV.
Key recommendations to get to 95-95-95 - South Africa

+ PLHIV lead complicated lives and may miss appointments and even miss taking some pills. When they do, meeting them with support when they return to the clinic helps ensure long term adherence. But PLHIV who return to the clinic and are treated badly, or who fear they will be, will often not come back.

+ All staff should be trained to provide a friendly and welcoming environment for all PLHIV and key populations whether accessing HIV prevention, accessing ART, or, most especially, returning to care after a treatment interruption. In addition no PLHIV should be sent to the back of the queue or shouted at if they miss an appointment.

+ Treatment literacy improves linkage and retention rates as people understand the importance of starting and remaining on treatment effectively, directly contributing to reaching the 95-95-95 targets. Healthcare workers must provide accurate + easily understandable information on treatment adherence and the importance of an undetectable viral load when talking to PLHIV, through counselling + health talks. In addition PEPFAR should fund community-led treatment literacy efforts!