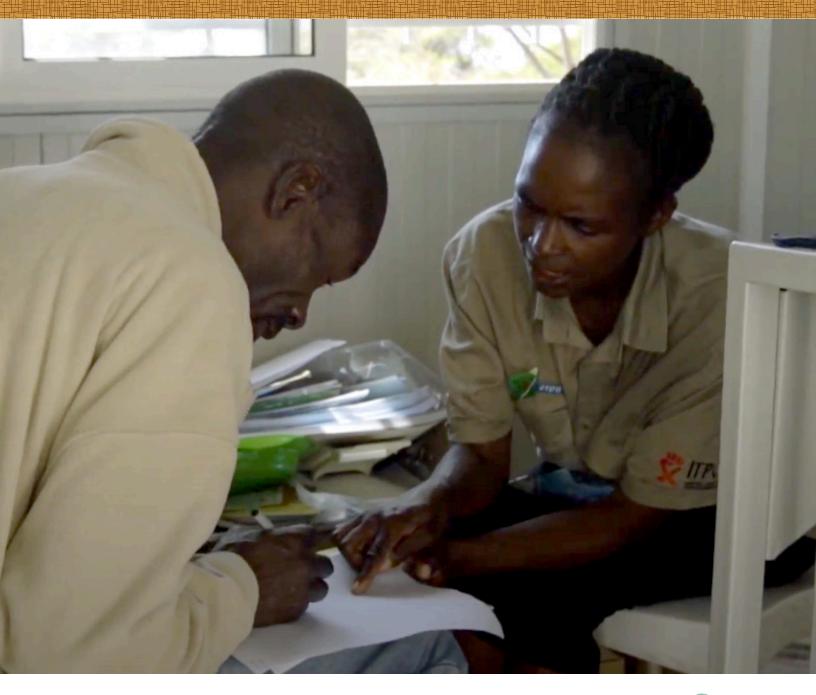
DONGLINGS DEERENISS

Key Findings from Community Treatment Observatories in Malawi, Zambia and Zimbabwe







ABOUT ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003

ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars:

- Treatment education and demand creation (#TreatPeopleRight)
- Intellectual property and access to medicines (#MakeMedicinesAffordable)
- Community monitoring and accountability (#WatchWhatMatters)

To learn more about ITPC and our work, visit itpcglobal.org.

ABOUT WATCH WHAT MATTERS

Watch What Matters is a community-led monitoring and research initiative to gather data on access and quality of HIV treatment globally. It defines a core strategic pillar of ITPC: ensuring that decisionmakers remain accountable to the communities they serve. Over the past decade, ITPC has implemented a number of community-led monitoring and research projects to improve access to and quality of treatment and services for HIV, hepatitis C virus and tuberculosis. Such projects include the Missing the Target research report series, stock-out monitoring in Eastern Europe and Central Asia, and community treatment observatories (CTOs) in West and Southern Africa.

Community-led monitoring of health systems increases government accountability and informs targeted advocacy actions that can improve HIV treatment, particularly for key and inadequately served populations. CTOs aim to streamline and standardize treatment access data collected by communities, ensuring that data is no longer collected in a fragmented way and better integrating questions and themes most important to those affected by HIV. It relies on a unique model that empowers communities to systematically and routinely collect and analyse qualitative and quantitative data on barriers to treatment access. Community data guides advocacy efforts and promotes accountability.

To learn more about Watch What Matters and our community-led monitoring work, visit www. WatchWhatMatters.org or send us an email at admin@itpcglobal.org.

ABOUT THIS REPORT

In partnership with the AIDS and Rights Alliance for Southern Africa (ARASA), ITPC presents in this report key results from the implementation of CTO interventions in Zimbabwe from March 2018 to December 2019 and in Malawi and Zambia from January 2019 to December 2019.

FOR MORE INFORMATION

Please contact us at admin@itpcglobal.org

ACKNOWLEDGEMENTS

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our regional partner, ARASA;

our national partners in Southern Africa:

- the Malawi Network of Religious Leaders Living with HIV and AIDS (MANERELA+)
- Zambia's Community Initiative for Tuberculosis, HIV/AIDS and Malaria plus related diseases (CITAM+)
- Zimbabwe's National Network of People Living with HIV (ZNNP+) and Zimbabwe Young Positives (ZYP+).

In particular, we recognize the tireless efforts of data collectors themselves and members of the national community consultative groups.

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- International AIDS Society (IAS)
- Robert Carr Fund (RCF)
- Open Society Foundations (OSF)
- Bridging the Gaps (BtG) Alliance.

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ABBREVIATIONS AND ACRONYMS

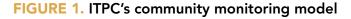
| 3TC | Lamivudine |
|-----------|---|
| ABC | Abacavir |
| AIDS | Acquired immune deficiency syndrome |
| ARASA | AIDS and Rights Alliance for Southern Africa |
| ART | Antiretroviral therapy |
| ARV | Antiretroviral |
| AZT | Zidovudine |
| CITAM+ | Community Initiative for Tuberculosis, HIV/AIDS and Malaria plus related diseases |
| сто | Community treatment observatory |
| DSD | Differentiated service delivery |
| HIV | Human immunodeficiency virus |
| IAS | International AIDS Society |
| ITPC | International Treatment Preparedness Coalition |
| LPV/r | Lopinavir/ritonavir |
| MANERELA+ | Malawi Network of Religious Leaders Living with HIV and AIDS |
| OSF | Open Society Foundations |
| RCTO-WA | Regional Community Treatment Observatory in West Africa |
| RVLT | Routine viral load testing |
| TDF | Tenofovir |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| WHO | World Health Organization |
| хтс | Lamivudine or emtricitabine |
| ZNNP+ | Zimbabwe's National Network of People living with HIV |
| ZYP+ | Zimbabwe Young Positives |
| | |

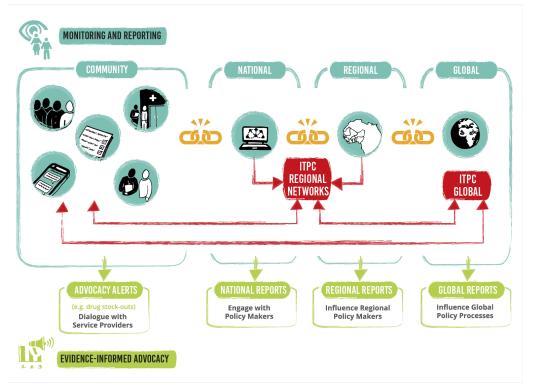
BACKGROUND

East and Southern Africa are home to 20.6 million people living with HIV, making it the world region most affected by the epidemic. According to Joint United Nations Programme on HIV/AIDS (UNAIDS) data, 85% of people living with HIV in East and Southern Africa are aware of their status, 67% are accessing antiretroviral therapy (ART) and 58% are virally suppressed.¹ Despite recent declines in new HIV infections and AIDS-related deaths, progress is still fragile and hindered by gaps in linkage to care and challenges with retention on treatment.

In 2018, the International Treatment Preparedness Coalition (ITPC) established a community treatment observatory (CTO) in Zimbabwe. A year later, the project expanded to include Zambia and Malawi through a partnership with the AIDS and Rights Alliance for Southern Africa (ARASA). Through the systematic monitoring of services by national networks of people living with HIV, they worked to improve HIV services, including scaling up of differentiated service delivery (DSD) and routine viral load testing. Supported by the International AIDS Society (IAS), the community-led monitoring platforms built on lessons learnt from ITPC's Regional Community Treatment Observatory in West Africa (RCTO-WA). The CTOs collected and analysed qualitative and quantitative data on availability, accessibility, acceptability, affordability and appropriateness of HIV care and services.

The observatories were implemented following ITPC's community-led monitoring model (Figure 1). National partners were selected based on their previous work on DSD and routine viral load testing advocacy. CTO implementation partners were the Malawi Network of Religious Leaders Living with HIV and AIDS (MANERELA+), Zambia's Community Initiative for Tuberculosis, HIV/AIDS and Malaria plus related diseases (CITAM+) and Zimbabwe's National Network of People Living





with HIV (ZNNP+) in collaboration with Zimbabwe Young Positives (ZYP+).² National networks in each country were responsible for collecting, analysing and using data for strengthened evidence-based advocacy.

Workshops to prepare for data collection were completed in February 2018 for implementation in Zimbabwe and in January 2019 for expansion to Malawi and Zambia. These workshops focused specifically on work planning and capacity building around community-led monitoring and evaluation, data collection and database use. Data quality audits were organized in each country in September and October 2019.

Based on specific criteria (such as population size and location), nine health facilities were selected as designated data collection sites. Implementing partners signed memoranda of understanding with each facility. Following the project launch, in-country partners established technical advisory boards, referred to as community consultative groups, to provide input into the development of data collection tools, support the implementation of the CTO, provide support on data analysis and give direction on organizational decisions.

ITPC sought formal ethics approvals in all three countries before starting data collection. Ethics approval was received from the National Health Sciences Research Committee in Malawi, the Medical Research Council in Zimbabwe and the Ministry of Health in Zambia.

From May 2018 to October 2019, the CTOs in Malawi, Zambia and Zimbabwe completed 96 monthly monitoring reports at nine facilities across the three countries. To complement quantitative data, national partners held 1,298 interviews and 179 focus group discussions with recipients of care, including young people age 15 to 24 years living with HIV (Table 1). Data was used to stimulate engagement at facility level, co-create solutions for care improvement, generate demand for services and encourage health system strengthening nationally.



Kelvin Makura, Zimbabwe Young Positives (ZY+), at the Zimbabwe National Network of People Living with HIV (ZNNP+) office in Harare, July 2019.

TABLE 1. The power of the CTO data

| | Malawi | Zambia | Zimbabwe | Total |
|---|---|---|--|--------|
| Data collection period | 6 months (May – October 2019) | 7 months (April – October 2019) | 17 months (May 2018 – September 2019) | |
| CTO-monitored districts | 1 (Kasungu) | 1 (Lusaka) | 2 (Harare, Mashonaland East) | 4 |
| CTO-monitored health facilities | 2 (Chamwabvi and Bua health centres) | 2 (Kalingalinga and Kanyama clinics) | 5 (Glenview, Beatrice, Hopley, Kunaka and Budiriro clinics) | 9 |
| CTO monthly reports from health facilities | 12 | 14 | 70 | 96 |
| HIV tests performed at CTO-monitored health facilities | 4,249 | 17,935 | 49,087 | 71,271 |
| People receiving ART at CTO-monitored health facilities (June 2019) | 1,047 | 24,588 | 15,682 | 41,317 |
| Young people receiving ART at CTO-monitored health facilities (June 2019) | 61 | 2,239 | 1,784 | 4,084 |
| Viral load tests | 492 | 10,288 | 8,643 | 19,423 |
| Interviews with RoCs ³ | 82 | 120 | 1 096 | 1,298 |
| Focus group discussions with RoCs | 11 | 28 | 140 | 179 |

KEY FINDINGS

To analyse the CTO data, this report uses the "Five As" conceptual framework: Availability, Accessibility, Acceptability, Affordability and Appropriateness. First developed by Penchansky and Thomas in 1981,⁴ this framework describes the fit between the person and the health system in five dimensions (Figure 2). ITPC has used this framework in the past to make sense of CTO data, most notably from the RCTO-WA.⁵

In this report, CTO findings are analysed along these five dimensions and punctuated by country-specific advocacy alerts from Malawi, Zambia and Zimbabwe.

🗢 Availability

Community-led monitoring aims to make health services, medicines, commodities and supplies available to those who need them when they need them. ITPC and its partners collected data on stock-outs of HIV tests, antiretroviral (ARV) medicines and lab supplies for HIV and viral load testing. Frequency of stock-outs was calculated from the number of reported stock-out episodes as a proportion of the total monthly CTO health facility reports per country.

HIV testing: Zimbabwe reported stock-outs of HIV test kits with a 4% frequency (three stock-out episodes out of 70 monthly facility reports). Zambia had frequent stock-outs of lab supplies for HIV testing (29%), which each lasted an average of eight days.

| Availability | Accessibility | Acceptability | Affordability | Appropriateness |
|--|---|--|--|--|
| | 1 P | 0 | \$ | -22 |
| Do the required health services, medicines, commodities and supplies exist? If so, do they exist when they are needed and in adequate supply? | Are there long travel distances or wait times? Are hours of operation convenient? Are referral processes along the care cascade smooth? | Is there a high quality of care? Are services provided free of stigma and discrimination? Are the human rights of patients promoted and protected? | Do services require out-of- pocket spending on behalf of the client? Is the service delivery model(s) efficient? What is the sustainability of the response? | Are services tailored to the specific needs of key and vulnerable populations? Are age and gender considered in service packages? |

FIGURE 2. The "Five As" – A person-centred conceptual framework for access

ADVOCACY ALERT

Swiftly engage various stakeholders to confront ARV stockouts in Zimbabwe

Confronted with recurrent episodes of second-line ARV stock-outs, ZNNP+ and ZYP+ took steps to stop shortages of ARVs in health facilities. They used CTO evidence to inform a petition to the Zimbabwean Parliament and engage strongly with the Ministry of Health and Child Care and the National Pharmaceutical Company.

As a result of these combined efforts, average duration of ARV stock-outs in Zimbabwe decreased from 37 days in period 1 (May to October 2018) to 24 days in period 3 (May to September 2019). This was despite the frequency of stock-outs increasing in the country.

ARV medicines: CTO data recorded a frequency of ARV stock-outs of 33% in Malawi and 23% in Zimbabwe, which lasted an average of 31 and 30 days respectively. The most common ARV stock-outs in Zimbabwe were: abacavir/lamivudine (ABC/3TC) (nine episodes) and tenofovir/lamivudine (TDF/XTC/ LPV/r) (five episodes). In Malawi, an episode of paediatric zidovudine/lamivudine (AZT/3TC) stock-out in the Chamwabvi Health Centre lasted 60 days. There were no reported ARV stock-outs in Zambia during the project period.

Routine viral load machines: CTO-recorded data showed that unavailability of enough functioning viral load test machines was an access barrier for 24% of people living with HIV respondents in Zimbabwe, 8% in Zambia and 4% in Malawi.

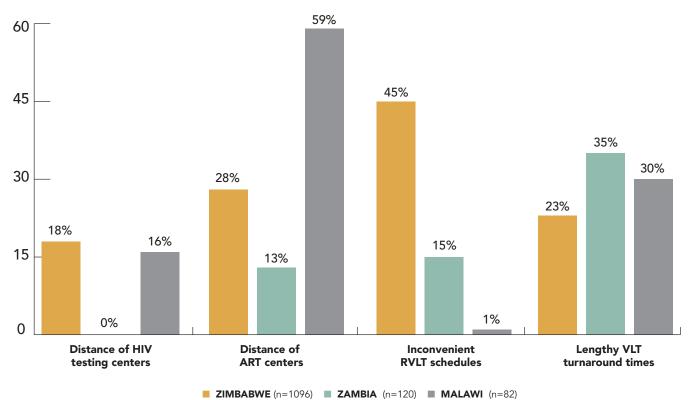


FIGURE 3. Accessibility barriers along the HIV care cascade

The number of available viral load testing machines varied per country and region monitored by the CTOs. There are 41 testing machines in Zambia, and five of them are in Lusaka. In Zimbabwe, there are 122 machines, but only six of them are in Harare and one is in Mashonaland East. In Malawi, the Kasungu District did not have any machines available; however, 13 machines are available nationwide, and samples from Kasungu are sent to Lilongwe or the Mzimba District in the Northern Region to be processed.

Accessibility

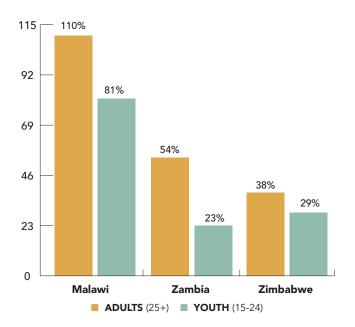
All three CTOs, through qualitative interviews and focus group discussions with recipients of care, identified challenges in accessibility of HIV care and services, particularly with regard to the length of travel distances to health facilities, length of waiting times, hours of operation and quality of referral processes.

Figure 3 shows the proportion of recipients of care who mentioned accessibility barriers for HIV care and treatment services in each country. When asked about barriers to HIV testing services, 18% of respondents in Zimbabwe and 16% in Malawi raised the issue of distance to testing centres. Distance to ART centres represented a barrier for 59% of people living with HIV interviewed in Malawi, 28% in Zimbabwe and 13% in Zambia. For routine viral load testing services, inconvenient schedules were a challenge for 45% of respondents in Zimbabwe, 15% in Zambia and 1% in Malawi. Long turnaround time of results was a barrier for 35% of people interviewed in Zambia, 30% in Malawi and 23% in Zimbabwe.

66 Receiving services in my community would reduce travelling long distances to get ARVs. My home is 10km away from the clinic. 99

> Adult male BUA HEALTH CENTRE, MALAWI

FIGURE 4. Treatment initiation rates per country, by age group



When comparing the two regions monitored by the CTO in Zimbabwe, accessibility issues came out consistently as stronger barriers at peri-urban than at urban facilities. For example, travel distance to HIV testing centres was mentioned as a barrier by 39% of respondents in Mashonaland East Province versus only 1% in Harare. Similar trends were observed regarding travel distance to ART centres (37% versus 6%), inconvenient routine viral load testing schedules (54% versus 38%) and lengthy routine viral load testing results turnaround times (24% versus 22%).

During the data collection period, the CTOs analysed the number of ART initiations as a proportion of the number of positive test results. Zimbabwe had the lowest treatment initiation rates throughout project implementation: 11,177 people tested HIV positive and 3,899 initiated treatment (35%). In Zambia, 5,612 people tested HIV positive and 2,585 initiated ARV treatment (48%). Malawi's treatment initiation rates were over 100%, most likely explained by good quality referral processes and a high number of external referrals. As shown in Figure 4, treatment initiation rates in all three countries were considerably lower for young people than for adults: 23% versus 54% in Zambia, 29% versus 38% in Zimbabwe and 81% versus 110% in Malawi (again, most likely explained by satisfactory linkage to care and external referrals).

Lack of knowledge about viral load guidelines among recipients of care was the most common barrier for routine viral load testing in all three countries: 56% in Malawi, 47% in Zimbabwe and 46% in Zambia.

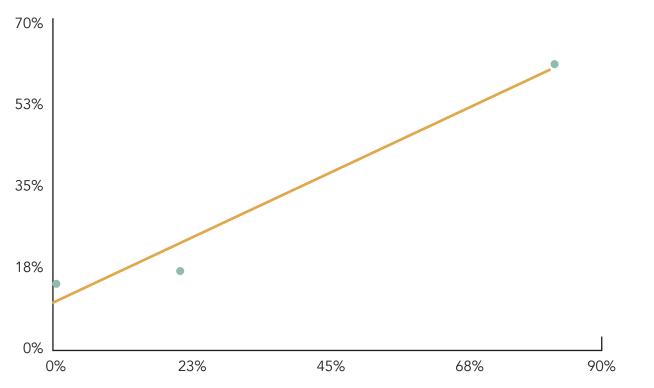
Viral load test results were often lost or received beyond the three-week threshold, making effective treatment monitoring difficult. In CTO-monitored facilities in Malawi, no results were received within the three-week threshold. The percentage of test results returned within three weeks was 21% in Zimbabwe and 83% in Zambia.

As shown in Figure 5, performance in routine viral load testing turnaround times is likely linked to viral suppression rates (<1,000 copies/ml): 14% in Malawi, 17% in Zimbabwe and 61% in Zambia.

TABLE 2. Number of HIV+ test results andART initiations, by age group

| | ADULTS (25+) | YOUTH (15-24) |
|-------------------|------------------------|-------------------------|
| MALAWI | | |
| HIV+ test results | 61 | 16 |
| ART initiations | 67 | 13 |
| ZAMBIA | | |
| HIV+ test results | 3,557 | 1,284 |
| ART initiations | 1,903 | 289 |
| ZIMBABWE | | |
| HIV+ test results | 7,301 | 3,728 |
| ART initiations | 2,752 | 1,088 |

FIGURE 5. Relationship between receiving timely routine viral load testing results and viral suppression rates



ADVOCACY ALERT

Improving accessibility of HIV care and routine viral load testing services in Malawi

Data from interviews and focus group discussions with recipients of care showed that inconvenient opening hours were a particular challenge for truck drivers and sex workers in accessing services in Malawi. MANERELA+ targeted policymakers at the Ministry of Health and at district level to address this. As a result, working hours within all public hospitals providing HIV services were extended in 2019, greatly improving accessibility of services for key populations.

CTO data was also key in advocating for changes in the national guidelines for viral load testing. After a tireless advocacy campaign from civil society, the Ministry of Health aligned the country's guidelines with WHO recommendations, from 24-month to 12-month testing. This will improve treatment monitoring and adherence among people living with HIV.

Acceptability

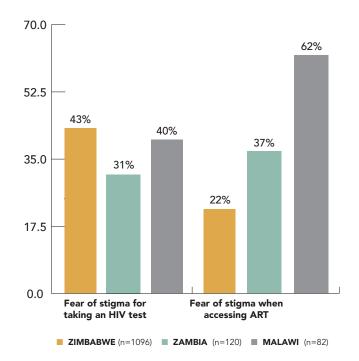
During interviews and focus group discussions, the CTOs asked recipients of care to rate the quality of services they received – ranging from 1 as the lowest to 5 as the highest. Average quality of care ratings were 4.41 in Malawi, 3.81 in Zambia and 3.56 in Zimbabwe.

In Zambia and Malawi, about a third of recipients of care rated quality of service provision at the relevant health facility at 3 or lower (36% and 28% respectively). In Zimbabwe, almost two-thirds of respondents (58%) rated quality of care at 3 and lower. In all three countries, male recipients of care rated services lower than their female counterparts (there were differences in average rating of 0.12 in Malawi, 0.11 in Zambia and 0.2 in Zimbabwe).

Side-effects were frequently mentioned as barriers to quality treatment. The percentage of respondents who mentioned them as reasons for not taking ARVs was 64% in Zimbabwe, 29% in Zambia and 10% in Malawi.

As shown in Figure 6, stigma and discrimination were identified as significant barriers to HIV testing and receiving ART: 62% of respondents in Malawi cited fear of stigma and discrimination when accessing ART as a barrier.

FIGURE 6. Stigma and discrimination as barriers to HIV testing and access to ART



Saffordability

TABLE 3. Payment or out-of-pocket expensesas barriers to HIV care and treatment services

| | HIV TESTING | ARVS | RVLT |
|-----------------------------|----------------|------|------|
| MALAWI (n=82) | 4% | 10% | 0% |
| ZAMBIA (n=120) | 0% | 3% | 5% |
| ZIMBABWE (n=1 096 | 5% | 26% | 17% |

Even if ARV medicines are available for free, payments for diagnostic tests, consultations with healthcare providers and medicines for opportunistic infections can have a huge negative impact on affordability of care. Overall, data from the CTO-monitored health facilities in Malawi and Zambia do not show fees or out-of-pocket expenses as major barriers to services. In Zimbabwe, where user fees are often charged for accessing HIV-related services, the proportion of respondents citing payment or out-of-pocket expenses as barriers to treatment was 5% for HIV testing, 26% for ARVs and 17% for routine viral load testing (Table 3).

Solution 6 ← We used to be treated for free when we fell sick, but now we are asked to pay. That is now demotivating us to come for treatment when we are not well.

Adult male BEATRICE CLINIC, ZIMBABWE

Appropriateness

Appropriateness refers to whether the health services provided are targeted and tailored to key and vulnerable populations most in need. The CTOs asked respondents where they preferred to receive services: directly at the facility or within their communities. The proportion of people living with HIV who preferred receiving services directly in their communities was 28% in Malawi, 24% in Zimbabwe and 22% in Zambia.

Additional trends emerge when looking at the age and sex of respondents: young people noted a higher preference for receiving services directly in their communities in Malawi and Zimbabwe when compared with adults (60% versus 21% and 32% versus 25%). In Zambia, the opposite is true, and only 16% of young people prefer services in their communities compared with 26% of adults. Finally, it is interesting to note that 37% of young Zimbabwean males said that they would prefer to receive services in their communities compared with only 16% of young females.

♦ Accessing services at community level will reduce cases of stigma and promote adherence because those that were defaulting due to distance will be back on treatment.

Focus group discussion with young males CHAMWABVI HEALTH CENTRE, MALAWI

When asking recipients of care if they were treated with respect by their healthcare workers, the percentage of those who answered negatively was 6% in Zambia, 5% in Zimbabwe and 1% in Malawi. These numbers go up considerably when looking specifically at adult females in Zambia (8%) or young females in Zambia (11%) and Zimbabwe (9%).

GOING FORWARD

The CTO model as implemented in Malawi, Zambia and Zimbabwe has proven successful in collecting, tracking, analysing and utilizing data for advocacy to improve quality and access to HIV treatment. With community data as an entry point, CTOs strengthen the links between recipients of care and health systems, improving their efficiency and resilience.

Concretely, evidence-based advocacy using CTO data allowed health facilities in Malawi to adjust their opening hours and expand accessibility for key populations. MANERELA+ also contributed with hard evidence to improve the country's national viral load testing guidelines. In Zambia, collecting data on access to HIV care and treatment services allowed CITAM+ to mobilize communities and decision-makers around DSD. For ZNNP+ and ZYP+ in Zimbabwe, the CTO work contributed to reducing the average duration of ARV stock-outs by 13 days at the monitored health facilities.

Funding partners should continue to invest in these initiatives as critical accountability mechanisms for improving gaps in treatments in the Southern Africa region. Our national partners are engaging tirelessly with governments and donors in an effort to ensure the sustainability of the CTOs. The CTO model is now seen as a credible and well-positioned mechanism to expand and support national and global investment in community-led monitoring. At national level, the CTO model was integrated into the 2020-2025 National Strategic Plans for HIV and AIDS in Malawi and Zimbabwe, opening the door to sustained support from other channels, such as the National AIDS Trust Fund in Zimbabwe.

In Malawi, the CTO model was included in the United States President's Emergency Plan for AIDS Relief's (PEPFAR's) Country Operational Plan 2020. Data from the CTO in Zimbabwe was included in the country's funding request to the Global Fund to Fight AIDS, Tuberculosis and Malaria, and CITAM+ in Zambia presented project results during a Country Coordinating Mechanism workshop in preparation for the Global Fund 2021-2023 request.

Through implementation of the CTO model in the three countries, we succeeded in setting up sustainable and cost-effective community-led monitoring to improve HIV and overall health programming, and in advocating for availability, affordability, accessibility, appropriateness and acceptability of services for everyone.

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ADVOCACY ALERT

Mobilizing communities for DSD in Zambia

Collecting data on access to HIV care and treatment services allowed CITAM+ in Zambia to carry out evidence-based advocacy activities and mobilize communities around DSD.

In 2019, CITAM+ was invited to participate in a National DSD Technical Working group, bringing in key insights from their community-led monitoring expertise. Joining the working group allowed CITAM+ to engage with various stakeholders working on DSD, and to receive valuable feedback from policy makers, including training manuals and pilot programs for communities. CITAM+ was also selected to present CTO results at the National HIV/ AIDS Conference that took place in Lusaka in December 2019.

ENDNOTES

- 1 UNAIDS (2018). Regional factsheets Africa: East and Southern. Online at https://aidsinfo.unaids.org/
- 2 In June 2017, MANERELA+, ZNNP+ and ZYP+ collaborated with ITPC and ARASA on the toolkit, What works for me: Activist Toolkit on Differentiated Service Delivery. Online at http:// itpcglobal.org/wp-content/uploads/2018/11/ITPC-DSD-Toolkit-Nov-2018.pdf
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- 5 ITPC (2019). Data for a Difference: Key Findings, Analysis and Advocacy Opportunities from the Regional Community Treatment Observatory in West Africa. Online at http://itpcglobal.org/resource/data-for-adifference/





