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Key Findings, Analysis and Advocacy Opportunities from the Regional Community Treatment Observatory in West Africa

JUNE 2019



#### **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 monitoring and research initiative to gather data on access and quality of HIV treatment globally. It defines a core strategic objective of ITPC to ensure that those in power remain accountable to the communities they serve.

Monitoring of health systems by communities increases government accountability and informs targeted advocacy actions that can improve HIV treatment, particularly for marginalized populations. Over the last decade, ITPC has been monitoring the scale up and quality of HIV treatment in different countries around the world from a community perspective. In South Asia and Eastern Europe and Central Asia (EECA), ITPC has monitored supply chain management issues and drug stock-outs. In 2015, with the support of Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ), community treatment observatories (CTOs) were formalized in East Africa, West Africa, Central Africa and Latin America.

Building on this work, Watch What Matters aims to streamline and standardize treatment access data collected by communities — helping ensure that data is no longer collected in a fragmented way and better integrates 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 analyze

gualitative and guantitative data on barriers to access. Data generated guides advocacy efforts and promotes accountability.

Currently, Watch What Matters is implementing a number of projects, including the Regional Community Treatment Observatory in West Africa (RCTO-WA), the Missing the Target (MTT) report series and a pilot community treatment observatory initiative in Zimbabwe.

To learn more about WWM and our work, visit WatchWhatMatters.org

#### **ABOUT THIS PUBLICATION**

In this publication, we share the findings and analysis from the first year of data collected by the RCTO-WA (July 2017–June 2018). The purpose of this paper is to tell the story behind the numbers.

We also chart the way forward for evidenceinformed and data-driven advocacy, drawing out the key messages and opportunities from the RCTO-WA data.

#### FOR MORE INFORMATION

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## **ABBREVIATIONS**

	NNRTI Non-nucleoside reverse-trans
AIDS Acquired Immune Deficiency Syndrome	<b>OIG</b> Office of the Inspector Gener
ART Antiretroviral therapy	<b>OPP</b> Open Polyvalent Platform
ARV Antiretroviral	PAC-CI Programme Agence national
CCG Community Consultative Group	PNLS
<b>CCM</b> Country Coordinating Mechanism	PrEP Pre-exposure prophylaxis
CD4 Cluster of differentiation 4	PSLS Programme santé de lutte co
CMS Central Medical Stores	PWID Poople who inject drugs
CTO Community treatment observatory	PWID People who inject drugs
DSD Differentiated service delivery	RAD Regional Advisory Board
DSQAs Data supervision and quality assessments	RAS+ Reseau des Associations de F
DTG Dolutegravir	RCTO-WA Regional Community Ireatme
ECOWAS Economic Community of West Africa States	<b>REBAP+</b> Réseau Béninois des Associat
EFV Efavirenz	<b>REGAP+</b> Réseau Guinéen des Associat et affectées par le VIH/SIDA
EECA Eastern Europe and Central Asia	<b>RENAP+GB</b> Rede Nacional das Associaçõ
GAMNASS Gambia Network of AIDS Support Societies	RIP+ Réseau Ivoirien des organisat
GIZ Deutsche Gesellschaft für Internationale Zusammenarbeit	RMAP+ Réseau Malien des Personnes
HIV Human Immunodeficiency Virus	RNP+ Réseau National des associat
HTS HIV testing services	<b>RST</b> Regional Support Team
IRB Institutional Review Board	SDG Sustainability Development G
ITPC International Treatment Preparedness Coalition	U=U Undetectable equals untransi
ITPC-WA International Treatment Preparedness Coalition West Africa	UN United Nations
JURTA Joint UN Regional Team on AIDS	<b>UNAIDS</b> Joint United Nations Program
LIBNEP+ Liberia Network of People Living with HIV	<b>UNAIDS RST</b> UNAIDS Regional Support Te
MSM Men who have sex with men	WAHO West Africa Health Organizat
MTT Missing The Target	WCA West and Central Africa
NAP+ Ghana National Network of Persons Living with HIV in Ghana	WHO World Health Organization
NETHIPS Network of HIV Positives in Sierra Leone	

scriptase inhibitor ral

le de recherche sur le sida Coopération Côte d'Ivoire Lutte contre le Sida

ontre le Sida

- Personnes Vivant Avec le VIH au Togo
- ent Observatory in West Africa
- tions de Personnes vivant avec le VIH
- itions de Personnes infectées
- ões das Pessoas Viventes com VIH Guinea-Bissau tions de Personnes vivant avec le VIH/SIDA es vivant avec le VIH
- tions de PVVIH du Sénégal
- Goal
- mittable
- mme on HIV/AIDS
- eam
- ion

## **IN BRIEF** Executive Summary

By the year 2020, the world must achieve the 90-90-90 targets in order to remain on track to end AIDS as a public health threat by 2030. Just one short year is left.

West and Central Africa remains far behind the rest of the world (and much of the rest of Africa) in terms of progress towards the 90-90-90 targets. Just 48% of people living with HIV are aware of their status and less than a third (29%) of all people living with HIV (PLHIV) in the region are virally suppressed. A confluence of factors stymies progress, including persistent stock-outs of medicines, high out-of-pocket expenditure, weak health systems, human rights barriers to access, and low quality of care.

Responding to these challenges, the International Treatment Preparedness Coalition (ITPC) launched a new community monitoring project in February 2017 called the Regional Community Treatment Observatory in West Africa (RCTO-WA). With support from the Global Fund to Fight AIDS, Tuberculosis and Malaria, the RCTO-WA aims to increase access to treatment in 11 West African countries: Benin, Côte d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Senegal, Sierra Leone and Togo. The three-year project has a

#### **BOX** The power of the RCTO-WA data set



particular focus on service uptake among key and vulnerable populations.

In each country, the national network of PLHIV was identified to lead implementation of the national Community Treatment Observatories (CTOs). After an extensive pre-implementation process, including technical trainings, the CTOs began collecting data from select health facilities in July 2017. The facilities were chosen based on specific criteria, such as population size and geographic location. The CTOs collect quantitative data (such as the number of HIV tests performed) on a monthly basis, and qualitative data (such as reasons for not accessing ART) on a quarterly basis.

The box below spotlights the power of the RCTO-WA dataset. In the first year of data collection, the RCTO-WA conducted 538 facility visits, 279 key informant interviews, and 110 focus group discussions. The data collected covers 161,607 people seeking HIV testing services, including 15,442 young people and 9,357 key populations.\* It captures treatment access, retention, and monitoring data for 81,817 people on ART.

\* The project collects data for three key populations — MSM, SW and PWID. Data is also collected for vulnerable populations such as adolescents and young people. For the purposes of this paper, the term "key and vulnerable populations" refers to these groups.

	81,817 PEOPLE ON ART
	16,491 VIRAL LOAD TESTS
*	15,442 YOUNG PEOPLE (AGE 15-24 YEARS)
<b>R</b> O	9,357 KEY POPULATIONS
	389 INTERVIEWS AND FOCUS GROUP DISCUSSIONS

In this publication, we share the findings and analysis from the first year of data collected by the RCTO-WA (July 2017–June 2018). The purpose of this paper is to tell the story behind the numbers. We also chart the way forward for evidence-informed and data-driven advocacy, drawing out the key messages and opportunities from the RCTO-WA data.

To analyze the RCTO-WA data, and to translate it into actionable advocacy messages, this paper uses the "Five As" conceptual framework— Availability, Accessibility, Acceptability, Affordability and Appropriateness. The "Five As" describe the fit between the person and the health system.

## Availability

The RCTO-WA documented the frequency of stock-outs along the cascade at 9% for HIV test kits, 24% for ARVs and 17% for viral load supplies. Stock-outs were most frequently recorded in Liberia and Togo (47% each), and least in Benin (0%) and Ghana (10%). On average, ARV stock-outs lasted for 41 days. In the most extreme case, one health facility in Côte d'Ivoire recorded a Tenofovir and Lamivudine stock-out lasting nearly 7 months. In countries where stock-outs were more frequently recorded, ART initiation rates were lower (r=-.876, p<.05).

On average, ARV stock-outs lasted for 41 days. In the most extreme case, one health facility in Côte d'Ivoire recorded a Tenofovir and Lamivudine stockout lasting nearly 7 months.

Among 296 interviews and focus group discussions, the most common responses given for why stock-outs occur was communication issues along the supply chain, followed by incorrect quantification and forecasting. Based on these data, advocacy efforts should focus on pushing the Joint UN Regional Team on AIDS (JURTA) to standardize inventory management tools for the region, and urging countries to develop and implement multistakeholder communication frameworks to improve quantification, orders, and deliveries of medicines along the supply chain.

## Accessibility

Qualitative RCTO-WA data show that the distance to the nearest health facility was cited as the top reason for not accessing HIV testing services (35%), as well as for not acce ssing ART (32%). As a result, key advocacy opportunities include pushing the West Africa Health Organization (WAHO), the UNAIDS Regional Support Team (RST) and Ministries of Health on expanding non-facility-based HIV testing options (including targeted community-based testing, and HIV selftesting) and differentiated service delivery (including longer refill times for stable patients and community ART pick-up points).

Linkage to care is also highlighted as a gap in the RCTO-WA data, flagging further accessibility issues. In countries where testand-treat is not yet fully rolled out, such as Liberia, significant gaps exist: Between January and June 2018, 1086 people tested positive for HIV but only 521 were initiated onto ART (48%). At RCTO-WA facilities, young people have lower treatment initiation rates (72%) than men who have sex with men (MSM) (89%) and sex workers (78%). Advocacy to translate test-andtreat policies into practice is needed.

RCTO-WA data show that the distance to the nearest health facility was cited as the top reason for not accessing HIV testing services (35%), as well as for not accessing ART (32%)

Access to viral load testing services is even more challenging. Among 81,817 people on ART, 16,491 viral load tests were performed between January and June 2018. While the RCTO-WA does not have data on when specific individuals began ART, these figures make it unlikely that the World Health Organization (WHO) recommendation of one viral load test every twelve months for stable patients is being met. Among 305 interviews and focus group discussions, 32% said that the reason for not accessing viral load testing services is that PLHIV lack knowledge of viral load guidelines. Just 26% of viral test results were returned within two weeks, making effective treatment monitoring very difficult. Indeed, of those who received a test, less than half (48%) were virally suppressed (<1000 copies/ml). RCTO-WA data show that in countries where viral load test results are more commonly returned within two weeks' time, the proportion of PLHIV on ART who have achieved viral suppression is higher (r=.66, p<.05). Low levels of effective treatment monitoring paired with frequent treatment interruptions and regular drug stock-outs is a recipe for ARV drug resistance. Advocacy efforts should push WAHO to support countries (financially and technically), to conduct HIV drug-resistance surveys, and to collect and analyze early warning indicators.

## Acceptability

RCTO-WA data show that more than a third of people consulted in interviews and focus groups rated quality of service provision at the relevant health facility as a 3 or less out of a possible 5. Quality of care was rated lowest in Sierra Leone (3.40/5.00) and highest in Mali (5.00/5.00). Quality of care was rated lowest among men who have sex with men (3.16/5.00) and highest among sex workers and pregnant women (4.00/5.00). Young women age 15-24 ranked quality of care slightly lower than young men (3.73/5.00 vs. 3.86/5.00). Ministries of Health must invest in additional training, paired with supportive supervision and group problem solving, so that healthcare workers are able to provide key population-competent and youth-friendly services.

RCTO-WA data show that more than a third of people consulted in interviews and focus groups rated quality of service provision at the relevant health facility as a 3 or less out of a possible 5.

Among 321 interviews and focus group discussions conducted, 30% of people/groups said that unbearable side effects were a top reason why they are not accessing ART. Communities should advocate for WAHO and JURTA to advance the availability of new and preferred treatment regimens, such as Dolutegravir (DTG), which are shown to have fewer side effects and greater barriers to resistance. As of mid-2018, five RCTO-WA countries (Benin, Côte d'Ivoire, Gambia, Guinea and Mali) are including or planning to include DTG containing regimens in their national protocols.

## S Affordability

Despite high out-of-pocket payments for health in the region, RCTO-WA data do not show payment on behalf of the client to be a major barrier to accessing services. This is a puzzling finding, which the RCTO-WA will explore further during focus group discussions in year two of data collection. Among 334 interviews and focus group discussions, payment is cited as a barrier among 2% of respondents for HIV testing services, 5% for ART, and 3% for viral load testing services.

Affordability may be a more significant factor on the provider side. RCTO-WA data show that less than 5% of RCTO-WA facilities (n=5/103) have functional viral load testing machines, with experts suggesting lack of funding as the main cause of this. In remote settings with low HIV prevalence and weak health systems, different models may be needed to scale up viral load testing access in a cost-effective and efficient manner, such as Open Polyvalent Platforms (OPPs) and dried blood spot samples. Advocacy can be directed at Country Coordinating Mechanisms, to include funding for these innovations in their next Global Fund funding requests.

In remote settings with low HIV prevalence and weak health systems, different models may be needed to scale up viral load testing access in a cost-effective and efficient manner.

## Appropriateness

RCTO-WA data sheds light on whether the health services provided are targeted and tailored to key and vulnerable populations most in need. In spite of countries' commitment in the Dakar Declaration to strengthen strategic information on key populations, just 38 out of 103 (37%) RCTO-WA facilities record such data. Among facilities that do record, significant gaps in linkage to care signal a need for intensified navigation from HIV testing services to ART initiation. 16% of all people who tested HIV-positive at the RCTO-WA facilities between April and June 2018 were men who have sex with men, sex workers, people who inject drugs and young people age 15-24. Yet, by June 2018, these groups made up just 7% of PLHIV on ART at the same facilities.

## In spite of countries' commitments in the Dakar Declaration, just 38 out of 103 (37%) RCTO-WA facilities report data for at least one key population.

Sub-analyses of RCTO-WA qualitative data show that key and vulnerable populations have different reasons for not accessing ART than the general population. Among 13 focus group discussions with young people, issues of confidentiality and privacy emerge as a top reason for not accessing ART. Among 19 focus group discussions held with MSM, sex workers and PWID, fear of stigma and discrimination emerged as a key reason. Advocacy efforts should urge Economic Community of West Africa States (ECOWAS) to enforce the Dakar Declaration, holding countries accountable for collecting data on key populations and investing in stigma reduction programs. Countries must include objectives to promote and protect human rights of PLHIV and key populations in costed HIV strategic plans.

## Way forward

This paper closes with a summary advocacy plan, prioritizing the top three key advocacy alerts from the paper for each of the 90-90-90 targets. The top advocacy priorities (for each 90) are to: (1) Expand the availability of non-facility-based HIV testing options, including community-led and communitybased HIV testing services; (2) Improve communication along the supply chain to prevent stock-outs of antiretrovirals; and (3) Increase funding to ensure the availability of adequate viral load testing machines and laboratory supplies. The advocacy priorities were set by the RCTO-WA's Regional Advisory Board (RAB)—a group of regional technical experts-on 23-24 October 2018 in Abidjan, Côte d'Ivoire. A more detailed plan is currently under development, with time-bound milestones, roles and responsibilities, and indicators to measure success.

Finally, a series of future possibilities for the RCTO-WA are highlighted. Sustaining this community action is critical. Without ongoing transparency, there can be no accountability. Going forward, the RCTO-WA has the potential to augment and deepen its impact, given the right partnerships and levels of investment. Opportunities to go beyond health facilities, understand the rural context, collect real-time data using digital technologies, create demand for services through health and treatment education, integrate tuberculosis into HIV services, collect early warning indicators for drug resistance, and look ahead to the 2025 Fast-Track targets (95-95-95) are discussed.

Sustaining this community action is critical. Without ongoing transparency, there can be no accountability.

## THE TIME IS NOW

Introduction

By the year 2020, the world must achieve the 90-90-90 targets:

- 90% of all people living with HIV will know their HIV status
- 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy
- 90% of all people receiving antiretroviral therapy will have viral suppression

Achieving these targets is imperative for remaining on-track to end AIDS as a public health threat by 2030—Sustainable Development Goal (SDG) 3.3. The 90-90-90 targets were initially set by the Joint United Nations Programme on HIV/AIDS (UNAIDS) in 2014,<sup>1</sup> but have since been formally committed to in national and regional plans and in the 2016 United Nations Political Declaration on HIV and AIDS.<sup>2</sup>

#### Just one short year is left.

To accelerate progress towards the 90-90-90 targets, Ministers of health from 12 countries in West Africa signed the Dakar Declaration on Factoring Key Populations in the Response to HIV and AIDS in April 2015, and UNAIDS launched a Western and Central Africa (WCA) Catch-Up Plan in October 2017. The Dakar Declaration commits countries to invest in stigma reduction, enhance community service provision, streamline health systems strengthening, include key populations in national strategic plans, and strengthen strategic information. The Catch-Up plan calls for the establishment of community monitoring systems for commodity stocks, service fees and quality of care.

Failure would have consequences for politicians, donors and technocrats, but by far

the greatest import is for communities living with HIV. Supporting these communities to monitor what matters to them is of immeasurable value in our collective goal. The evidence on this is clear—when communities are resourced to monitor what is happening in their environments, it leads to better health outcomes.<sup>3,4,5,6,7</sup>

Community-based monitoring and feedback creates greater transparency and accountability. It also sheds light on myriad other dimensions of progress: funding, efficiency, surveillance mechanisms, people's motivation and understanding, demand, quality of care, use of new technologies, human rights- and gender-related barriers to access, emerging issues, unanticipated bottlenecks, inequities, inequalities, and much more. Put simply, you get insight into why things are working (or not working).

Strong health and community systems are a prerequisite for achieving the 90-90-90 targets, as well as the other Fast-Track targets, the UN Political Declaration commitments, and the health SDGs.

Towards achieving the 90-90-90 targets, and creating strong systems to sustain this progress, this paper

shares a year's worth of monitoring data from 11 West African countries, that was collected and analyzed by networks of people living with HIV through the Regional Community Treatment Observatory in West Africa (RCTO-WA). We also chart the way forward for evidence-informed and data-driven advocacy, drawing out the key messages and opportunities from the RCTO-WA data.

The time is now. Let's act.

## **A REGION LEFT BEHIND** Background and Context of the HIV Epidemic in West Africa

The WCA region remains far behind the rest of the world (and much of the rest of Africa) in terms of progress towards the 90-90-90 targets (Figure 1).

Knowledge of one's HIV status is the main "leak" in the cascade. Fewer than half of people living with HIV (PLHIV) in West and Central Africa are aware of their status. This is the lowest rate of any region in the world. Stock-outs of test kits, user fees, limited demand, limited counselling and support and reluctance of health care workers to propose HIV testing, all contribute to an underemphasis on HIV testing services (HTS) in the region.8 Twin gaps exist for related diseases. In 2017, WCA had nearly 600,000 missing people with TB<sup>9</sup>—those affected by the disease who go undiagnosed and untreated.

### FIGURE 1 Progress Towards The 90-90-90 Targets (2017)<sup>13</sup>



Persistent stock-outs of medicines create adherence challenges and low levels of viral suppression in the region. Audits and reviews of grants to West African countries from the Global Fund to Fight AIDS Tuberculosis and Malaria highlight these issues (Table 1).

Insufficient monitoring of commodity stocks is

For the few who do access HIV testing services, a fair number (83%) are navigated into care and are receiving sustained antiretroviral therapy (ART). As of July 2018, sixteen countries<sup>10</sup> in the WCA region have adopted test-and-treat for all people diagnosed with HIV.<sup>11</sup> This has improved treatment access by ensuring that more people have access to treatment sooner. For example, the median time to treatment in Senegal decreased from 5.6 months in 1998-2003, to 0.8 months in 2014-2015.<sup>12</sup>

Yet, viral suppression remains below the global average and below the rest of sub-Saharan Africa. With "leaks" at all stages along the cascade, the bottom line is that less than a third (29%) of all PLHIV in West and Central Africa are virally suppressed.

also a challenge. A 2017 World Bank and the World Health Organization (WHO) report tracking universal health coverage found that insufficient data is currently available to report on access to a core set of relevant essential medicines, including ARVs (SDG indicator 3.b.3). Fewer than 30 countries globally have collected primary data since 2010.<sup>14</sup>

#### TABLE 1 Stock-out Challenges in Global Fund Grants to West African Countries

COUNTRY	YEAR	FINDINGS OF THE OFFICE OF THE INSPECTOR GENERAL (OIG)
BENIN	2012	The OIG noted conflicting evidence on the extent of stock-outs. All development partners interviewed emphasized a persistent and wide spread shortage of health products since October 2011, yet the national AIDS program (Le Programme National de Lutte contre le Sida [PNLS]) reports for the same period indicated that only 9% (61 of 678) sites experienced any stock-outs. During the visits to 4 centers, the OIG team noted that even before stocks were entirely depleted, services dependent on those stocks were curtailed. Patients thus experienced service limitations even before stock-outs became reportable <sup>.15</sup>
CÔTE D'IVOIRE	2016	Significant stock-outs in mid-2016 at the national level, including unavailability of HIV tests for more than one month <sup>.16</sup>
GAMBIA	2012	The OIG observed good stock coverage, with no ARV stock out in the Central Medical Stores (CMS) and in ART Centers (though some expiry). The quantity of drugs delivered by the central level was well recorded on stock cards. Gambia received a donation of pediatric ARVs from WAHO, which had a positive impact on stock coverage of ARVs for adults, but added to the overstocking of pediatric ARVs. This resulted in some ARVs expiring before use <sup>-17</sup>
GHANA	2015	27% of locations tested did not use stock cards and 18% of locations tested did not have records of physical stock verifications. 41% of locations did not have a stock ledger <sup>.18</sup>
GUINEA	2017	There is an estimated US\$3 million in potential expiry of ARVs financed by the Global Fund in 2016, representing 38% of the ARVs procured under the HIV grant as of April 2017. HIV rapid test kits were below the minimum stock level at the central medical stores. This resulted in order fill rate of 0-21% and stock-out at the facilities visited for an average of 37 days. <sup>19</sup>
GUINEA- BISSAU	2014	The OIG found no material stock-outs of essential medicines. However, 64% of the health clinics visited maintained stock cards, but only 18% understood how to manage them properly. Where in place, 93% of stock cards did not match the underlying products, 82% were not correctly completed and 36% of stock cards were not available for core medicines. <sup>20</sup>
MALI	2017	In January 2017, some facilities in the Segou region faced stock-outs of pediatric ARVs. There has also been a stock-out since February 2017 of HIV testing reagents at the central warehouse in Bamako. In May 2017, there was a national stock-out of government-financed third-line ARVs for a month <sup>-21</sup>
SENEGAL	2012	All health facilities visited were fully stocked with ARVs in appropriate quantities. No stock-outs were observed or reported in any of the pharmacies visited, which implies that quantification of ARVs is appropriate to the demand. There were, however, frequent reports of stock-outs of reagents for CD4 analysis. <sup>22</sup>
тодо	2011	Most intermediaries did not maintain proper records and it was therefore impossible to determine the stock status at any point in time. <sup>23</sup>

Uptake of pre-exposure prophylaxis (PrEP) as a new prevention technology remains relegated to small demonstration projects among MSM and sex workers in Benin, Côte d'Ivoire, Mali and Togo.<sup>24</sup> As of October 2018, generic PrEP registration is planned in Côte d'Ivoire and pending in Senegal.

High out-of-pocket expenditure on health characterizes the region, creating additional barriers to access. In 2015, out-of-pocket expenditure (as a percentage of current health expenditure) was higher than 50% in Guinea and Togo, and higher than 40% in Benin, Mali and Senegal.<sup>25</sup>

Treatment interruptions due to regular stockouts coupled with poor treatment monitoring due to limited access to viral load testing services is a recipe for ARV drug resistance. A recent meta-analysis estimated a pretreatment drug resistance prevalence of 7.2% (2.9–16.5%) among people initiating or re-initiating non-nucleoside reverse-transcriptase inhibitors (NNRTIs) in Western and Central Africa in 2016<sup>.26</sup> NNRTIs efavirenz and nevirapine are the current backbone of first-line therapy and peripartum prophylaxis in mothers and

## **FIGURE 2.** Avertable Mortality in Western sub-Saharan Africa<sup>69</sup>



Deaths due to non-utilization of health services

Deaths due to poor-quality services

newborn babies for prevention of mother-tochild transmission of HIV.

The WHO recommends standardized surveys to assess pretreatment drug resistance and acquired resistance in adults and children and so-called early warning indicators of HIV drug resistance, with the aim of obtaining nationally representative estimates that inform strategies to improve ART service delivery and guide selection of first-line, second-line, and thirdline regimens. Yet, in West Africa, reporting on these indicators is not taking place, with lack of funding for the surveys as a barrier.<sup>27,28</sup>

Underpinning many of these challenges along the cascade is a crisis in quality of care. A 2018 study found that of the 812,987 deaths in Western sub-Saharan Africa that were preventable by health care, 458,235 (56.4%) were due to non-utilization of health services and 354,744 (43.6%) were due to poor quality of services (Figure 2)<sup>29</sup> Universal health coverage may not yield the desired results if the services provided are of such poor quality.

Chronic shortfalls of health workers also limit access to services. In Mali, there are just 0.05 health workers per 1000 population. In Liberia, there are 0.08 per 1000 population. For context, the global average health worker density was 5.9 per 1000 population in 2015, and the SDG target for this indicator is 10.9 per 1000 population by the year 2030<sup>-30</sup> To help mitigate this, 13 countries<sup>31</sup> in WCA have implemented task-shifting guidelines, enabling services to be provided by nurses or community lay workers.<sup>32</sup>

Stigma and discrimination are key human rights and gender-related barriers to access along the cascade. Results from the people living with HIV stigma indices highlight these challenges (Table 2).

#### TABLE 2. Stigma and Discrimination as a Barrier to Health Services in West Africa

COUNTRY	YEAR	PERCENTAGE OF PEOPLE SURVEYED IN THE PLHIV STIGMA INDEX WHO SAID THEY HAVE BEEN DENIED HEALTH SERVICES DUE TO THEIR HIV STATUS
Gambia	2012	6.0% <sup>33</sup>
Ghana	2014	1.4% <sup>34</sup>
Liberia	2013	6.0% <sup>35</sup>
Senegal	2012	3.0% <sup>36</sup>
Sierra Leone	2013	2.0% <sup>37</sup>

The 2014 West Africa Ebola outbreak shone a spotlight on the fragile nature of the region's health and community systems. The outbreak was both a symptom of existing health systems weaknesses as well as a cause of enduring systems-related challenges for the HIV response<sup>.38</sup> If universal health coverage is to be realized, significant investments are needed to build and sustain more robust and resilient systems for health.

## WATCHING WHAT MATTERS

Responding to the challenges in the previous section, in February 2017, ITPC launched a new community monitoring project called the Regional Community Treatment Observatory in West Africa (RCTO-WA), with the support of the Global Fund to Fight AIDS, Tuberculosis and Malaria,. The RCTO-WA elevates communities of people living with HIV as leaders in accountability.

## How community treatment observatories work

Housed under the Watch What Matters campaign, the RCTO-WA follows ITPC's Community Monitoring Model (Figure 3).

### FIGURE 3. ITPC's Community Monitoring Model



## The Regional Community Treatment Observatory in West Africa

Community treatment observatories (CTOs) serve as a watch-dog mechanism for health and social service delivery systems. Where communities are often neglected, marginalized, or disconnected from decisionmaking processes, CTOs provide communities a way to ensure that health systems respond to their needs and rights. CTOs provide a comprehensive picture of both the quantity and quality of services being provided in the setting. In this way, they can track uptake of services while also monitoring quality of care. Additionally, CTOs help to streamline and standardize all treatment access data and ensure that the questions and themes important to those most affected by HIV are integrated into the process.39

## Aims of the project

Building on previous work monitoring stockouts of ARVs in the region, the RCTO-WA aims to increase access to treatment in 11 West African countries: Benin, Côte d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Senegal, Sierra Leone and Togo.

The RCTO-WA aims to increase access to treatment by:

- Formalizing and expanding community treatment observatories (CTOs) in all focus countries
- Creating a regional treatment observatory
- Building the capacity of 11 national PLHIV networks to do treatment monitoring

The three-year project has a particular focus on access to services and quality of care among five key and vulnerable populations: men who have sex with men (MSM), sex workers, people who inject drugs (PWID), pregnant women and young people (age 15-24 years). These populations are at greater risk of HIV infection and face greater challenges to accessing HIV prevention and treatment services. Importantly, key populations are not passive subjects of RCTO-WA data collection; at the time of writing, 20 MSM, 15 sex workers and 2 PWID are active members of the CTO data collection teams.

## Setting up the RCTO-WA

Before launching in February 2017, the RCTO-WA underwent an extensive pre-implementation process. This included the development of management documents to guide and frame the scope and implementation of the project, in-depth organizational capacity assessments conducted by the Global Fund Technical Review Panel and Local Fund Agent, and development of performance framework and work plan tracking measures.

In each of the 11 West African countries, the national network of PLHIV was identified as

in-country partners to lead implementation of the national CTOs (Table 3). A series of three technical planning workshops were completed between December 2016 and February 2017 to train implementation teams from each country. These workshops focused specifically on work planning and capacity building around monitoring and evaluation, data collection, database use, financial management, and governance.

Following the project launch, in-country partners established technical advisory boards referred to as community consultative groups (CCGs), 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. At the regional level, a Regional Advisory Board (RAB) made up of technical experts in the region was established, to guide the development of data tools, validate the collected data, and provide a critical steer on key advocacy opportunities.



### TABLE 3 National CTO Host Organizations in the RCTO-WA

СТО	HOST ORGANIZATION
BENIN	Réseau Béninois des Asso
CÔTE D'IVOIRE	Réseau Ivoirien des organ
GAMBIA	Gambia Network of AIDS
GHANA	National Network of Perso
GUINEA	Réseau Guinéen des Asso par le VIH/SIDA (REGAP+
GUINEA-BISSAU	Rede Nacional das Associon of Associations of PLHIV c
LIBERIA	Liberia Network of People
MALI	Réseau Malien des Person
SENEGAL	Réseau National des assoc
SIERRA LEONE	Network of HIV Positives i
TOGO	Réseau des Associations c

## **Ethics Approval**

ITPC submitted the project protocol to all Ministries of Health or National AIDS Programs before starting data collection. Ethics approval was waived in all but five countries, where ITPC sought formal approvals from Institutional Review Boards (IRBs). Ethics approval was received from Comité National d'éthique pour la recherche en santé in Benin, Comité national d'éthique de la recherche in Côte d'Ivoire, The Ghana Health Service Ethical Review Committee, Comité Nacional de Ética na Saúde in Guinea-Bissau, and The University of Liberia IRB.

## **Data Collection**

After significant investments in establishing and training eleven CTOs, data collection began in

pciations de Personnes vivant avec le VIH (REBAP+)

isations de Personnes vivant avec le VIH/SIDA (RIP+)

Support Societies (GAMNASS)

ons Living with HIV in Ghana (NAP+ Ghana)

ociations de Personnes infectées et affectées ·)

iações das Pessoas Viventes com VIH (Network of Guinea Bissau) (RENAP+GB)

Living with HIV (LIBNEP+)

nes vivant avec le VIH (RMAP+)

ciations de PVVIH du Sénégal (RNP+)

in Sierra Leone (NETHIPS)

de Personnes Vivant Avec le VIH au Togo (RAS+)

July 2017. Based on specific criteria (such as population size, location) 103 health facilities were selected as designated data collection sites. ITPC has signed memorandums of understanding with each facility.

Data was collected from the selected sites using standardized paper-based tools (developed in English, French, and Portuguese) which were then scanned into an electronic web-based database and archiving system. The RCTO-WA database includes an online dashboard (also developed in English, French, and Portuguese) where all partners enter data for both quantitative and qualitative indicator sets.

One data collection tool was used to collect quantitative data (such as number of HIV tests performed) from health facilities on a monthly basis, and a separate tool was used to collect qualitative data (such as reasons for not accessing ART) from key informant interviews and focus groups discussions on a quarterly basis. Both the quantitative and qualitative tools monitor issues along the entire continuum, specifically prevention, testing, ART initiation, and treatment monitoring. Key informants and focus group participants were convenience sampled from the monitored health facilities and were made up of a combination of service users and services providers.

From July 2017-June 2018, the RCTO-WA conducted 538 facility visits, 279 key informant interviews, and 110 focus group discussions. In this paper, qualitative data is presented from the entire year, but quantitative data is only presented from January-June 2018 (due to refinement of data collection tools during the first six months of implementation). Age disaggregation for young people was added to the tools in March 2018, and the indicator on HIV-positive test results was added in April 2018. The data was cleaned and validated by the CTOs, with formal in-person data supervision and quality assessments conducted by ITPC project staff on a routine basis.

## Limitations

The RCTO-WA acknowledges the following limitations:

- Varying sizes of the different CTOs. The 103 health facilities monitored by the RCTO-WA are not evenly distributed across the 11 countries. For example, there are 19 health facilities monitored in Côte d'Ivoire, and 3 in Benin. Comparative analyses in this report should be seen in that light.
- Varying capacities of the different CTOs. The host organizations for the eleven CTOs vary in capacity, leading to different levels of data collection. For instance, the CTO in Togo conducted 67 key informant interviews between July 2017 and June 2018, whereas

the CTO in Liberia conducted 1. In addition, some CTOs updated their data collection tools faster than others. The CTOs in Ghana and Guinea-Bissau, for example, have not yet begun collecting data on the number of HIV-positive test results, while most of the other CTOs have.

- Sampling bias. The sample of people in the RCTO-WA is of people who are already accessing health services (since data collected at health facilities). This may oversample people who already demonstrate health-seeking behavior, or who have already overcome certain barriers to access. Further, the RCTO-WA intentionally samples health facilities that serve key population groups (in order to collect this disaggregated data). This may also lead to an over-representation of key population groups in the region.
- Data quality. The reality in West Africa is that most health facilities keep paper-based patient records. The CTO data collectors transcribe these records by hand, then enter them into the computer later on. The possibility for human error in data entry both by the health facility, and by the CTO—is a challenge. The CTOs provide data checks, and the RCTO-WA provides DSQAs, to help minimize errors and ensure data quality.
- Lack of unique identifiers. The health facilities monitored by the CTOs do not have unique patient identifiers. This means that the RCTO-WA dataset cannot be sure that the number of HIV tests or the number of viral load tests are unique individuals. As such, the dataset can paint an overall picture of access, uptake and retention in services, but cannot track individual clients along the cascade.

## **Data Analysis**

Initial data analysis was conducted by ITPC's local academic partner, Programme Agence nationale de recherche sur le sida Coopération Côte d'Ivoire (PAC-CI). ITPC-WA provided additional interpretation, followed by an external analysis by an independent consultant.

The data was then validated by the RAB during its third meeting in October 2018 in Abidjan, Côte d'Ivoire. Based on the validated data, the RAB developed a draft advocacy plan. This paper brings together the findings from the various data analyses, as well as the advocacy priorities identified by the RAB.

## A Conceptual Framework for Access

To truly understand the story that the RCTO-WA data is telling, a conceptual framework for access is helpful. The "Five As" framework has specific dimensions, describing the fit between the person and health system (Figure 4).

### FIGURE 4. "The Five As" — A Person-Centered Conceptual Framework for Access

Availability	Accessibility	Accepta
	A.	(3)
<ul> <li>Do the required health services, medicines, commodities and supplies exist?</li> <li>If so, do they exist when they are needed and in adequate supply?</li> </ul>	<ul> <li>Are there long travel distances or wait times?</li> <li>Are hours of operation convenient?</li> <li>Are referral processes along the care cascade smooth?</li> </ul>	<ul> <li>Is there a quality o</li> <li>Are servi provided of stigma discrimin</li> <li>Are the h rights of patients promote protecte</li> </ul>

The "Five As" have been used by many global health organizations, institutions, and thinkers, to theorize access to and quality of health care. It was first developed by Penchansky and Thomas in 1981<sup>40</sup> but has since informed a variety of studies, policies and guidance documents for human rights-based and person-centered approaches to health.<sup>41,42,43,44</sup> The framework is flexible, and has been applied to the health workforce.<sup>45</sup> vaccine uptake.<sup>46</sup> community-based long-term care.<sup>47</sup> antenatal and postnatal care,<sup>48</sup> universal access to HIV prevention, treatment and care.<sup>49</sup> and many other areas.

In this paper, the RCTO-WA findings are presented and analyzed along these five dimensions. The findings are punctuated by data-driven advocacy alerts, helping to turn data into a difference.



## TABLE 4. Sample Characteristics of the RCTO-WA

INDICATOR	BENIN	CÔTE D'IVOIRE	GAMBIA	GHANA	
	NUMBER (%)				
QUALITATIVE DATA (Cumulative, July 2017-June 2018)					
Number of key informant interviews	ND*	33 (12%)	7 (3%)	18 (6%)	
Number of focus group discussions	ND	27 (25%)	9 (8%)	11 (10%)	
<b>QUANTITATIVE DATA</b> (Cumulative, January-June 20	018)				
Number of health facilities in sample	3 (3%)	19 (18%)	13 (13%)	7 (7%)	
Number of visits to health facilities for data collection	12 (2.2%)	105 (19.5%)	68 (12.6%)	39 (7.2%)	
People who received an HIV test	1,691 (1%)	48,562 (30%)	18,291 (11%)	16,527 (10%)	
MSM	173 (8%)	203 (10%)	ND	14 (1%)	
Sex workers	745 (11%)	2,063 (32%)	2 (0%)	100 (2%)	
PWID	0 (0%)	0 (0%)	ND	ND	
Young men (15-24)70	101 (2%)	982 (20%)	584 (12%)	0 (0%)	
Young women (15-24)	277 (3%)	3,987 (38%)	1,844 (17%)	0 (0%)	
People living with HIV receiving ART (as of June 2018)	1,766 (2%)	23,098 (28%)	5,939 (7%)	2,627 (3%)	
MSM	21 (2%)	383 (41%)	ND	ND	
Sex workers	82 (13%)	403 (64%)	ND	ND	
PWID	ND	0 (0%)	ND	ND	
Young men (15-24)	13 (1%)	315 (23%)	54 (4%)	ND	
Young women (15-24)	10 (0%)	677 (26%)	241 (9%)	ND	
People on ART who received a viral load test	144 (1%)	8908 (54%)	554 (3%)	804 (5%)	
MSM	0 (0%)	97 (46%)	ND	ND	
Sex workers	0 (0%)	102 (56%)	ND	ND	
PWID	0 (0%)	0 (0%)	ND	ND	
Young men (15-24)	1 (0%)	104 (50%)	4 (2%)	6 (3%)	
Young women (15-24)	4 (1%)	209 (53%)	19 (5%)	0 (0%)	

GUINEA	GUINEA- BISSAU	LIBERIA	MALI	SENEGAL	SIERRA LEONE	TOGO	TOTAL
			NL	IMBER (%)			
14 (5%)	ND	1 (0%)	127 (46%)	ND	12 (4%)	67 (24%)	279 (100%)
8 (7%)	ND	ND	12 (11%)	32 (29%)	8 (7%)	3 (3%)	110 (100%)
	1						
13 (13%)	2 (2%)	6 (6%)	5 (5%)	16 (16%)	20 (19%)	11 (11%)	103 (100%)
55 (10.2%)	12 (2.2%)	38 (7.1%)	18 (3.3%)	55 (10.2%)	91 (!6.9%)	45 (8.4%)	538 (100%)
6,394 (4%)	918 (1%)	8,554 (5%)	9,009 (6%)	11,508 (7%)	27,681 (17%)	12,472 (8%)	161,607 (100%)
139 (7%)	ND	12 (1%)	492 (24%)	99 (5%)	457 (22%)	488 (23%)	2,077 (100%)
336 (5%)	ND	1 (0%)	691 (11%)	18 (0%)	30 (0%)	2,505 (39%)	6,391 (100%)
12 (2%)	ND	ND	4 (1%)	193 (24%)	580 (74%)	ND	789 (100%)
135 (3%)	ND	429 (9%)	96 (2%)	361 (7%)	1,157 (24%)	1,032 (21%)	4,877 (100%)
264 (2%)	ND	388 (4%)	147 (1%)	134 (1%)	2,508 (24%)	1,016 (10%)	10,565 (100%)
5,676 (7%)	3,226 (4%)	3,615 (4%)	7,036 (9%)	5,789 (7%)	9,510 (12%)	13,535 (17%)	81,817 (100%)
0 (0%)	ND	16 (2%)	168 (18%)	190 (21%)	12 (1%)	130 (14%)	920 (100%)
0 (0%)	ND	1 (0%)	100 (16%)	3 (0%)	ND	41 (7%)	630 (100%)
0 (0%)	ND	ND	ND	3 (6%)	49 (94%)	ND	52 (100%)
11 (1%)	ND	1 (0%)	278 (20%)	20 (1.4%)	499 (36%)	209 (15%)	1400 (100%)
61 (2%)	ND	2 (0%)	336 (13%)	0 (0%)	974 (38%)	291 (11%)	2592 (100%)
603 (4%)	ND	83 (1%)	1917 (12%)	923 (6%)	1922 (12%)	633 (4%)	16,491 (100%)
0 (0%)	ND	ND	58 (30%)	14 (7%)	32 (15%)	11 (5%)	212 (100%)
0 (0%)	ND	ND	70 (38\$)	2 (1%)	0 (0%)	8 (4%)	182 (100%)
0 (0%)	ND	ND	ND	4 (2%)	189 (98%)	0 (0%)	193 (100%)
4 (2%)	ND	ND	49 (24%)	12 (6%)	21 (10%)	6 (3%)	207 (100%)
4 (1%)	ND	ND	33 (8%)	0 (0%)	115 (29%)	11 (3%)	395 (100%)

\*no data

## DATA FOR A DIFFERENCE

Findings and Analysis from the RCTO-WA

When communities work together—and are adequately supported—their power to collect and analyze data is nothing short of remarkable. The first year of data collected by the RCTO-WA from July 2017 to June 2018 spans a significant cross-section of the HIV epidemic and response in West Africa.

Covering 11 countries, 103 health facilities, and more than 81,817 people living with HIV on ART, the data collected by the RCTO-WA is representative of the regional situation at a population level and with a very strong degree of certainty.<sup>50</sup> Further details of the sample characteristics are in Table 4.

During the observed period, RCTO-WA health facilities performed 161,607 HIV tests, supported 81,817 people on ART, and performed 16,491 viral load tests. As the largest treatment observatory in the sample, Côte d'Ivoire is responsible for about a third of the HIV tests and people on ART, and about half of the viral load tests.

Disaggregated data for key and vulnerable populations, including men who have sex with men (MSM), sex workers, people who inject drugs (PWID) and young people age 15-24 years was available from some CTOs. In some

countries, this data was not available from the health facilities. Among key populations, a greater number of sex workers were reached with HIV testing services, while more MSM were reached with ART. For PWID, four CTOs recorded HIV testing data (Guinea, Mali, Senegal and Sierra Leone) and two (Senegal and Sierra Leone) recorded ART and viral load testing information. About twice as many young women were reached with services compared to young men.

In April 2018, the RCTO-WA began collecting data on HIV-positive test results (Table 5). The CTO in Liberia reports an HIV positivity rate among all tests performed between April and June 2018 of 26.5%. Guinea recorded 20%. In Benin, the proportion of positive test results recorded among MSM is more than twice the UNAIDS prevalence estimate (9.4% vs. 4.2%). In other places, the proportion of positive test results is lower than would be expected, including among sex workers in Côte d'Ivoire, and among PWID in Sierra Leone. With the small(er) sample size and a short timeframe (just three months), this indicator likely needs more data collection before trends can be observed and more concrete conclusions can be drawn.



For the availability dimension, RCTO-WA data sheds light on whether the required health services, medicines, commodities and supplies existed, and if so, whether they existed when they are needed and in adequate supply. The following stock-outs were recorded during monthly RCTO-WA health facility visits between January and June 2018:

**Stock-outs of HIV test kits:** Out of 535 visits, stock-outs of HIV test kits were recorded in 47 instances (9% frequency) (27 for rapid tests, 20 for blood tests).



FIGURE 6. Frequency of Recorded Stock-outs of ARVs (in the last month) During RCTO-WA Monthly Monitoring Visits, January-June 2018, by Country



- **Stock-outs of ARVs:** Out of 538 visits, stockouts of ARVs were recorded in 126 instances (23% frequency) (see Figure 6 and 7 for breakdown by country and by drug).
- **Stock-outs of viral load test supplies:** Out of 536 visits, stock-outs of viral load test supplies were recorded in 92 instances (17% frequency) (52 reagents and chemicals, 20 consumables, 25 durables and 5 unspecified).

Stock-outs of ARVs were the most common at RCTO-WA health facilities, compared to stockouts of HIV test kits and viral load lab supplies (Figure 5).

FIGURE 5. Frequency of Recorded Stock-outs Along the Cascade at RCTO-WA Health Facilities

## **FIGURE 7.** Frequency of Recorded Stock-outs of ARVs (in the last month) During RCTO-WA Monthly Monitoring Visits, January-June 2018, by Drug



- Darunanavir 2%
- Efavirenz 5%
- Lamivudine 4%
- Lamivudine/Zidovudine/Abacavir 3%
- Lamivudine/Zidovudine/Nevirapine) 165
- Lopinavir/Ritonovir 12%
- Nevirapine 16%
- Tenofovir 3%
- Tenofovir/Lamivudine 3%
- Tenofovir/Lamivudine/Efavirenz 3%

On average, ARV stock-outs at RCTO-WA facilities last for 41 days. However, the speed with which recorded stock-outs are resolved varies greatly. Nineteen recorded ARV stockouts were resolved within two weeks, but 29 lasted longer than 50 days. Seven lasted longer than 100 days. In the most extreme case, one

#### FIGURE 8. Length of ARV Stock-outs at RCTO-WA Facilities, January-June 2018



### TABLE 5. HIV-Positive Test Results at RCTO-monitored Health Facilities (April-June 2018)

	BENIN	CÔTE D'IVOIRE	GAMBIA	GHANA		
POPULATION	HIV-POSITIVE TEST RESULTS					
	NUMBER (%)					
All	109 (9.3%)	997 (3.2%)	491 (5.7%)	ND		
MSM	15 (9.4%)	23 (13.8%)	0 (0.0%)	ND		
Sex workers	22 (5.7%)	14 (0.7%)	0 (0.0%)	ND		
PWID	0 (0.0%)	0 (0.0%)	0 (0.0%)	ND		
Pregnant women	14 (3.7%)	86 (1.2%)	42 (1.1%)	ND		
Young men (15-24)	7 (7.0%)	9 (0.9%)	6 (1.0%)	ND		
Young women (15-24)	11 (4.0%)	64 (1.6%)	28 (1.5%)	ND		
Young men (15-24)71	101 (2%)	982 (20%)	584 (12%)	0 (0%)		
Young women (15-24)	277 (3%)	3,987 (38%)	1,844 (17%)	0 (0%)		

GUINEA	GUINEA- BISSAU	LIBERIA	MALI	SENEGAL	SIERRA LEONE	TOGO	TOTAL
			(Note: not	t necessarily ur	nique individual	s)	
	-		NU	MBER (%)			
643 (20.0%)	ND	1086 (26.5%)	250 (9.2%)	ND	905 (6.8%)	280 (4.4%)	4741 (5.7%)
13 (20.0%)	ND	1 (9.1%)	21 (7.8%)	ND	5 (2.1%)	17 (5.6%)	95 (7.6%)
10 (11.0%)	ND	0 (0.0%)	40 (10.0%)	ND	1 (25%)	11 (1.4%)	98 (2.6%)
0 (0.0%)	ND	0 (0.0%)	0 (0.0%)	ND	9 (2.5%)	0 (0.0%)	9 (2.0%)
93 (11.5%)	ND	18 (2.1%)	14 (1.3%)	ND	129 (3.2%)	40 (2.2%)	436 (1.6%)
15 (11.1%)	ND	5 (1.2%)	5 (5.2%)	ND	74 (6.4%)	9 (1.0%)	130 (2.7%)
27 (10.2%)	ND	30 (8.7%)	14 (9.5%)	ND	226 (9.0%)	14 (1.5%)	414 (4.0%)
135 (3%)	ND	429 (9%)	96 (2%)	361 (7%)	1,157 (24%)	1,032 (21%)	4,877 (100%)
264 (2%)	ND	388 (4%)	147 (1%)	134 (1%)	2,508 (24%)	1,016 (10%)	10,565 (100%)

health facility in Côte d'Ivoire recorded a Tenofovir and Lamivudine stock-out lasting nearly 7 months (210 days). Gambia and Sierra Leone typically resolve stock-outs in under a month, whereas the average time to resolve a stock-out in Togo is 67 days (Table 6).

THAN 2	0 DAYS		
UTS LA	STING MORE THAN 50 E	DAYS	
	STOCK-OUTS LASTING	5 MORE THAN 100 DA	YS
7			
	7		

#### DATA FOR A DIFFERENCE 21

#### TABLE 6. Length of Recorded Stock-outs at RCTO-WA Facilities, January-June 2018

COUNTRY	AVERAGE NUMBER OF DAYS THAT ARVS REMAIN OUT OF STOCK
BENIN	No recorded stock-outs
CÔTE D'IVOIRE	53 Days
GAMBIA	26 Days
GHANA	32 Days
GUINEA	34 Days
GUINEA-BISSAU	39 Days
LIBERIA	31 Days
MALI	37 Days
SENEGAL	37 Days
SIERRA LEONE	25 Days
TOGO	67 Days

RCTO-WA qualitative data from interviews and focus group discussions shed light on why ARV stock-outs are occurring. Among 296 interviews and focus group discussions, the most common response given was that there are communication issues along the supply chain (29%). This is followed by incorrect quantification and forecasting (16%) (Figure 10).

#### FIGURE 9. Relationship Between Recorded ARV Stock-outs and Treatment Initiation Rates at **RCTO-monitored Facilities**



(n=296 interviews/focus group discussions)



prevent stock-outs of antiretrovirals

RCTO-WA data show that the frequency of stock-outs is extremely high for ARVs, and there is a link between ARV stock-outs and treatment initiation rates (Figure 9). The top reason cited for ARV stock-outs is communication issues along the supply chain. JURTA must standardize inventory management tools for the region. Ministries of Health must work with health facilities, central medical stores and communities to identify communication barriers between actors along the supply chain. Countries must develop and implement multi-stakeholder communication frameworks to improve quantification, orders and deliveries of medicines along the supply chain.

### FIGURE 10. Reasons Given For ARV Stock-outs at RTCO-WA Facilities, July 2017-June 2018

## **ADVOCACY ALERT** Improve communication along the supply chain to

## TOGO

At the Sylvanus Olympio University Teaching Hospital in Lomé, Togo, the PMTCT unit uses the CTO data that is collected and analyzed by RAS+ to cross-check data in its central reporting system. By triangulating their patient-level data with the CTO's analysis, the hospital became aware of a problem: some HIV-positive pregnant women who were on ART were, mistakenly, also being tested for HIV. CTO data is now used by the service supervisor to avoid such mistakes. Given limited supply of diagnostics, the CTO analysis has helped prevent wastage through errors. Togo is among three countries in the RCTO-WA (along with Benin and Gambia) where there have been no recorded stock-outs of HIV test kits during the first year of data collection.

# SUCCESS STORY 0

## BENIN

At the Bethesda Hospital in Cotonou, Benin, CTO host REBAP+ noticed that the site had not been supplied with lab reagents for more than 10 months. This meant that patients were not receiving critical treatment monitoring services, including viral load and CD4 count test. The CTO data on reagent stock outs was recorded in REBAP+'s report, for presentation to the CTO's Community Consultative Group (CCG). During this meeting of the CCG, the Deputy Coordinator of The National AIDS Control Program (Programme santé de lutte contre le Sida-PSLS) was confronted with REBAP+'s CTO data on reagent stock-outs. The CCG's function as a feedback mechanism for the CTO worked, and a solution was found. After the meeting, PSLS stocked Bethesda Hospital with reagents.

## Accessibility

Only 48% of PLHIV in West and Central Africa have received an HIV test and are aware of their status—the lowest coverage of any region in the world.

RCTO-WA data highlight accessibility to HIV testing services as a key barrier to uptake.

### FIGURE 11. Reasons Given For People Not Receiving an HIV Test, July 2017-June 2018 (n=289 interviews/focus group discussions)



**ADVOCACY ALERT** 

**HIV testing services** 

RCTO-WA data show that long distances to health facilities is the top reason people are not accessing HIV testing services. Push WAHO to issue guidance on how to make community-based HTS targeted and tailored to high-risk populations. Opportunities exist to integrate community-based HTS with community TB screening, too, which can help to find the missing people with TB. Advocate for Ministries of Health to update their HIV testing guidelines to prioritize targeted community-based HTS, especially led by community organizations, youth, and key populations networks. In the medium term, ensure countries make HIV self-testing options available, guided by the anticipated results from current pilot projects in Côte d'Ivoire, Mali and Senegal.

Among 289 interviews and focus group discussions conducted by CTO data collectors between July 2017 and June 2018, more than a third (35%) of all respondents said that long distances to the health centers where HTS is performed is the main reason why people are not accessing this service (Figure 11).

## Expand the availability of non-facility-based HIV testing options, including community-led and community-based

## **ADVOCACY ALERT**

## Intensify HIV communication and awareness campaigns to increase demand for HIV testing services

In 2017, just 48% of PLHIV in West and Central Africa knew their status—the main cascade leak. A quarter of people consulted in RCTO-WA key informant interviews and focus group discussions said that fear of discovering one's status is the reason people do not go for HIV testing services. Misconceptions about HIV

in the region are persistent and contribute to this fear. The UNAIDS Regional Support Team (RST) must convene a regional meeting of key stakeholders to strategize on how to address this issue as a key barrier to HTS. Based on the outcomes, UNAIDS RST must implement a regional campaign, with common language and standardized messaging. WAHO must fund Ministries of Health and National AIDS Councils to launch national HTS campaigns, particularly targeted at stigma reduction and key and vulnerable populations.

As with HIV testing, distance to the health facility is also cited as a common reason for not accessing ART. Among 321 interviews and focus groups conducted by CTO data collectors between July 2017 and June 2018, 32% of all respondents said that long distances

to the ART center is the main reason why people are not accessing this service (Figure 12). Treatment literacy and quality of care is also a clear gap, with 30% citing side effects of treatment as a reason for not receiving ART.

### FIGURE 12. Reasons Given For People Not Receiving ART, July 2017-June 2018 (n=321 interviews/focus group discussions)



**ADVOCACY ALERT** 

RCTO-WA data show that long distances to health facilities is the top reason people are not accessing ART. Longer refill periods for stable patients and more convenient pick-up points could improve access to ART. WAHO must issue normative regional guidance on differentiated service delivery, including

standardized information on longer refills for stable patients and community-based ART options. The UNAIDS Regional Support Team (RST) must convene key stakeholders to agree on consistent community-friendly messaging around the undetectable=untransmutable (U=U) campaign in the context of differentiated service delivery (DSD) in West Africa. Ministries of Health must ensure that national DSD policies are adhered to by facilities.

## **SIERRA LEONE**

**STORY** 

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The host of the national CTO in Sierra Leone, NETHIPS, has been engaged in sustained advocacy efforts with the government to formally adopt a National Differentiated Service Delivery Strategy. Making use of CTO data that showed the low uptake of services for key populations, NETHIPS has made the case to the National AIDS Control Program of the Ministry of Health and Sanitation that such a strategy is needed in order to reduce barriers to accessing services and to achieve the 90-90-90 targets. On 4 March 2019, at the National HIV/AIDS Control Program conference hall, NETHIPS turned CTO data into an advocacy win, securing a commitment from the government to develop a DSD policy for Sierra Leone. The policy was signed by government and the National AIDS Secretariat in May 2019. As next step, NETHIPS will now work closely with key partners to mobilize the resources needed to implement Sierra Leone's new DSD policy.

A key aspect of the "Accessibility" dimension is to understand how smooth referral processes are, and if patients are retained in care along the cascade. At the time of writing, eight of the eleven RCTO-WA countries have fully or partially adopted current WHO guidelines to implement the test-and-treat policy: Côte d'Ivoire, Gambia, Ghana, Guinea, Liberia (for priority populations, with full rollout planned

## Strengthen community systems and responses to support the roll-out of differentiated service delivery

for 2019), Senegal, Sierra Leone and Togo. However, RCTO-WA data highlight that what is written on paper is not necessarily implemented in practice; between April and June 2018, 4,692 people tested positive for HIV at RCTO-WA monitored health facilities and 4,354 were initiated onto ART (93%). In some countries, gaps in linkage to treatment are very large. In Sierra Leone, 905 people tested positive and

647 were initiated onto ART (71%). In countries where test-and-treat is not yet fully rolled out as national policy, one can see even bigger gaps. In Liberia, 1086 people tested positive and 521 were initiated onto treatment (48%).

Among key and vulnerable populations, larger treatment initiation gaps are observed in the data.

From April-June 2018, RCTO-WA data show that:

- 95 MSM tested positive for HIV and 85 were initiated onto ART (89%)
- 98 sex workers tested positive for HIV and 76 were initiated onto ART (78%)
- 414 young people age 15-24 tested positive for HIV and 300 were initiated onto ART (72%)

Key and vulnerable populations face specific challenges with linkage and navigation into

care, often as a result of human rights- and gender-related barriers. These require tailored and often peer-led solutions. These issues are further explored in the "Appropriateness" dimension.

Once initiated onto ART, treatment monitoring must be accessible to the client. RCTO-WA highlight a stark drop-off from the number of PLHIV receiving ART at RCTO-WA monitored health facilities (n=81,817) to the number of PLHIV that received a viral load test in the past six months (n=16,491) (Figure 13); just 20% of PLHIV on ART had a viral load test in the last six months. While the RCTO-WA does not have data on when specific individuals began ART, these figures make it unlikely that the WHO recommendation of one viral load test every twelve months for stable patients is being met.

Of those who received a viral load test, less than half (48%) were virally suppressed—far lower than the UNAIDS estimate of 73%.

### FIGURE 13. Access to Viral Load Testing Services and Viral Load Suppression Data at RCTO-WA monitored Health Facilities (as of June 2018)



FIGURE 14. Reasons Given For People Not Receiving a Viral Load Test, July 2017-June 2018 (n=305 interviews/focus group discussions)



RCTO-WA data show that lack of information testing services (Figure 14). Lack of knowledge on about routine viral load monitoring prevents viral load guidelines is also at the root of many of people from demanding or accessing it. Among the human resources challenges cited in Figure 305 interviews and focus group discussions 14. ITPC has developed an approach to conducted by CTO data collectors between July community-led demand creation for the use of 2017 and June 2018, 97 people/groups (32%) routine viral load testing, which can help address cited lack of knowledge among PLHIV as the top this gap<sup>.51</sup> reason why people are not receiving viral load



## **ADVOCACY ALERT** Enhance knowledge among PLHIV and healthcare workers to increase demand for high quality viral load

testing services

RCTO-WA data show that one in five people living with HIV on ART had a viral load

test in the past six months. The main reason for not receiving a test is lack of knowledge of viral load testing guidelines among PLHIV, as well as among healthcare workers. People living with HIV must have up-to-date health and treatment education, including knowledge of viral load testing guidelines about when and how often they are entitled to a viral load test. ITPC's successful community-led demand creation model should be used to do this. In addition, health centers must train their staff on viral load monitoring, and provide supportive supervision to ensure providers are conducting viral load testing at the right time.

Figure 14 also shows that nearly 1 in 10 people cite the delay in return of results as the reason for not accessing viral load testing services. Indeed, the RCTO-WA data show that just 4.362 of 16.491 (26%) viral load tests had results returned to the patient within two weeks. RCTO-WA data also show a relationship

between receiving timely viral load test results and prevalence of viral load suppression (Figure 15). In countries where viral load test results are more commonly returned within two weeks' time, the proportion of PLHIV on ART who have achieved viral suppression is higher (r=.66, p<.05).

### FIGURE 15. Relationship Between Receiving Timely Viral Load Test Results and Prevalence of Viral Load Suppression at RCTO-WA Facilities, January-June 2018



## **ADVOCACY ALERT**

## Ensure effective treatment monitoring through acceptable turn-around times for viral load test results

RCTO-WA data show that one in four viral load tests have the results returned to the patient within two weeks. Long turnaround times for viral load test results are related to poorer treatment monitoring and poorer outcomes for the patient, especially lower levels of viral load suppression. WAHO must support countries (financially and technically), to conduct HIV drug-resistance surveys and to collect

and analyze early warning indicators. Laboratories must batch and streamline samples, sending timely results back to facilities. Health care providers must notify the client of their test result as soon as it is received from the laboratory. Information communication technologies (such as WhatsApp) can be used to do so.

## Acceptability

There is increasing recognition that quality of care is a vital component of health services delivery. In Western sub-Saharan Africa, nearly as many deaths (that are amenable to health care) are caused by poor quality care as are caused by non-utilization of health services (43.6% vs. 56.4%).<sup>52</sup>

At the time of writing, only six CTOs (Côte d'Ivoire, Gambia, Mali, Senegal, Sierra Leone and Togo) covering just 24 health facilities were collecting data on the quality of care indicator. Going forward, the RCTO-WA intends to expand data collection on this indicator in order to verify results and trends.

Among 58 interviews and focus group discussions conducted by CTO data collectors at 24 health facilities between July 2017 to June 2018, 37% of people/groups rated quality of service provision at the relevant health facility as a 3 or less out of a possible 5 (Figure 16).

Quality of care ratings in the RCTO-WA data differ greatly depending on the country and depending on the population. Quality of care was rated as lowest in Sierra Leone (3.40/5.00)

## Health Facilities, by country (n=58 interviews/focus group discussions)



and highest in Mali (5.00/5.00) (Figure 17). It is acknowledged that larger sample sizes are needed to verify these results.

### FIGURE 16. Average Rating (out of 5) of the Overall Quality of Services Provided at RCTO-WA Health Facilities (n=55 interviews/ focus group discussions)



FIGURE 17. Average Rating (out of 5) of The Overall Quality of Services Provided at RCTO-WA

CTOs in Togo and Côte d'Ivoire disaggregated the quality of care rating by key population. At 15 health facilities in these two countries, quality of care was lowest among men who have sex with men (3.16/5.00) and highest among sex workers and pregnant women (4.00/5.00) (Figure 18). Young women age 15-24 ranked quality of care slightly lower than young men age 15-24 (3.73/5.00 vs. 3.86/5.00), possibly indicating a gender-related barrier to accessing acceptable health services. Healthcare workers may require additional training to ensure they are able to deliver key population-competent, youth-friendly, and gender-sensitive health services.

#### FIGURE 18. Average Rating (out of 5) of The Overall Quality of Services Provided at RCTO-WA Health Facilities, by population (n=58 interviews/focus group discussions)



Global data suggest that a lack of health worker motivation is often a bigger predictor of poor-quality service delivery than lack of knowledge. There is a persistent, often sizeable, gap between what health care providers say they will do when faced with a hypothetical patient and what they actually do when they see such a patient.<sup>53</sup> In one study, providers were four times more likely to order

vignette that with an actual patient.<sup>54</sup> This has been called the "know-do" gap. In some cases, the "know-do" gap is so large that that providers without any formal medical training can provide higher quality care than fully trained doctors.<sup>55</sup> Enhancing supportive supervision and group problem solving has been shown to help close the gap.<sup>56,57</sup>

the correct Tuberculosis treatment in a clinical

Good reception by the maternity mediators - Well received by the women - Only at the time of the strike there was a lack of personnel.

Respondent ranked service quality a "3", Togo

Testing must be done alone to prevent conflict of result at the testing site.

> Respondent ranked service quality a "4", Sierra Leone

## **ADVOCACY ALERT**

of care

RCTO-WA data show that more than a third of people rank the overall quality of services provided as a 3 out of 5 or less. Quality of care is lower for key and vulnerable populations, especially MSM and young women. Ministries of Health must invest in

additional training so that healthcare workers are able to provide key population-competent, youthfriendly, and gender-sensitive services. They must also enhance supportive supervision and group problem solving sessions to ensure health workers deliver services in line with their training. WAHO must conduct research to determine the extent of the "know-do" gap in West Africa.

## **GAMBIA**

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The host of the national CTO in Gambia, GAMNASS, has used CTO data to shine a spotlight on facility-level quality improvement needs. The CTO's most recent quarterly report, for the period January-March 2019, was shared with ART centers country-wide, the National Public Health Laboratory, National AIDS Secretariat, Ministry of Health, UN System in the Gambia and the Local Government Authorities. GAMNASS also presented the report to the National Assembly Health Select Committee at the National Assemble building. This high-level data-driven advocacy by GAMNASS has resulted in two specific commitments from National Assembly Health Select Committee. First, the Committee promised to engage the Ministry of Health and National AIDS Secretariat on performance improvement plans for health facilities. Second, the Committee promised to engage the Ministry of Finance on additional budgetary allocation to the HIV response.

Recall from the previous section that among 321 interviews and focus group discussions conducted, 30% of people/groups said that unbearable side effects were a top reason why they are not accessing ART. This treatment

> The facility, as said, is doing fine after the invention of ITPC. They said the MSM are given good attention after one of their members is working at the facility. That gave them hope because he helps them to get their services.

## Ensure healthcare workers are adequately trained and provided with supportive supervision to improve quality

access issue has a link to quality of care, if newer drug regimens are available which could lessen the side effects experienced and help retain people on treatment.

Respondent ranked service quality a "5", Gambia

The HIV integrase inhibitor Dolutegravir (DTG) could help increase the acceptability of firstline ART. This drug has fewer side effects and a higher genetic barrier to resistance than efavirenz (EFV). It may even reduce advanced HIV disease prevalence by lowering rates of treatment discontinuation and treatment failure. The most recent WHO guidelines (released August 2018) state that DTG is the

preferred first-line antiviral therapy for HIV/ AIDS in adults and adolescents. Yet, few countries have moved to full rollout of DTG, and there is concern surrounding its safety in pregnant women.<sup>58</sup> As of mid-2018, five RCTO-WA countries (Benin, Côte d'Ivoire, Gambia, Guinea and Mali) are including or planning to include DTG containing regimens in their national protocols.<sup>59</sup>

## **ADVOCACY ALERT**

## Ensure the availability of new and preferred treatment regimens, including Dolutegravir (DTG)

RCTO-WA data show that poor side effects are a significant reason for people not receiving ART, cited by almost a third of those consulted. Dolutegravir, the now WHO-recommended first-line treatment, has fewer side effects and a higher genetic barrier to resistance. JURTA must seek pooled procurement opportunities in the region to enable countries to switch to DTG as a first line treatment (and possibly

second line for people who have been treated with Efavirenz). WAHO must issue safety guidance for women living with HIV of childbearing potential, that does not compromise their reproductive rights.

SUCCESS STORY OF.

## MALI

The host of the national CTO in Mali, RMAP+, has used CTO data to improve quality of care in health facilities by improving data quality and individual patient monitoring. During a recent CTO monitoring visit to the Gabriel Touré University Teaching Hospital in Bamako, RMAP+ drew the attention of health facility managers to data entry issues. Viral load test results were being transferred from patient registers to the central viral load databases in groups, clustered by date. Using their CTO data analysis, RMAP+ pointed out that it is better to record this data individually, by patient.

The reaction from the health facility after RMAP+'s advocacy was swift; without waiting for a memo from the hospital, the nurses began to systematically report the dates of the viral load results by individual patient. Based on this success story at Gabriel Touré, RMAP+ intends to target the Cellule Sectorielle de

Lutte contre le SIDA (The Sectoral Unit for AIDS Control of the Ministry of Health and Public Hygiene) and the Société Malienne des Sciences Appliques (The Malian Society of Applied Sciences) to develop a memo to be sent to all sites in Mali, clarifying how viral load data should be entered and analyzed.

## S Affordability

Despite high out-of-pocket expenditure on health in the West Africa region, affordability is not cited as a major barrier to access at RCTO-WA monitored health facilities. This is a puzzling finding, which the RCTO-WA will explore further during focus group discussions in year two of data collection.

### FIGURE 19. Proportion of people who cited payment or considerable out-of-pocket expenditure as a reason for not accessing services along the cascade (n=334 interviews/focus group discussions)



Between June 2017 and July 2018, across 334 interviews and focus group discussion, just 2% cited payment as a barrier to accessing HIV testing services, just 5% for ART, and just 3% for viral load testing services (Figure 19).

Cost of services is just one component of affordability. Many of the key informants and focus group discussion participants who mentioned distance as a barrier to access said this is connected to the costs of transportation.

RCTO-WA data do not highlight financial challenges as a major reason for ARV stockouts at monitored health facilities. Indeed, just 2% of 296 survey respondents said that reliance on donors for support was the reason for stock-outs. This is contrary to other studies, which found that the unpredictability of fund disbursements and the frequency of grant performance monitoring performed by the Global Fund leads to intrinsic stock-out risks in Africa.<sup>60</sup>

For viral load testing services, availability of resources appears to be a larger constraint. RCTO-WA data show that less than 5% of RCTO-monitored sites (5/103) have functional viral load testing machines. Out of 305 key informant interviews and focus group discussions, 27% of people/groups cited no or broken viral load machines as the reason they cannot access viral load testing services.

**RCTO-WA Regional Advisory Board experts** suggest lack of funding for viral load testing machines, maintenance of those machines, and lab reagents and other supplies is a main cause of this.

In remote settings with low HIV prevalence and weak health systems, different models may be needed to scale up viral load testing access in a cost-effective and efficient manner. Open Polyvalent Platforms (OPPs) are an innovative open laboratory system that can be used to perform HIV viral load testing as well as a host of other molecular tests including those for diagnosing tuberculosis and viral hepatitis. For trained laboratory technicians, the system is flexible and easy to use and maintain. Countries are increasingly investing in OPP technology to scale up viral load testing access, some through their national Global Fund grants.<sup>61</sup>

In addition, evidence suggests that dried blood spot samples can be used as alternative specimens to plasma to increase access to HIV viral load monitoring in remote or rural settings.<sup>62</sup> This innovation should be scaled up in West African region.

## **ADVOCACY ALERT**

Increase funding to ensure the availability of adequate viral load testing machines and laboratory supplies

RCTO-WA data show that just 5 viral load machines serve more than 100 health facilities in the 11 focus countries, and just 20% of PLHIV in the RCTO-WA sample had a viral load test in the past six months. Nearly a third of people asked say that no or broken viral load machine are the main reason they are not accessing viral

load testing services, with experts pointing to a lack of resources as the reason for this. Country Coordinating Mechanisms (CCMs) must consider including Open Polyvalent Platforms (OPPs) in their Global Fund proposals, to decentralize access to viral load testing services. Ministries of Health should implement new innovations such as dried blood spot samples to increase access to viral load monitoring in remote settings.



The final dimension—appropriateness examines whether the health services provided are targeted and tailored to key and vulnerable populations most in need.

With data on 15,442 young people and 9,357 MSM, sex workers and PWID, the RCTO-WA dataset is among the largest sources of information on these groups' access to services in the region. In spite of the commitment of countries in the Dakar Declaration to

## **ADVOCACY ALERT**

Hold countries accountable for their Dakar Declaration commitment to strengthen strategic knowledge and information on key populations

RCTO-WA data show that just 38 out of 103 (37%) RCTO-monitored facilities

record data for at least one key population. The Dakar Declaration commits countries to strengthen strategic knowledge and information on key populations. As envisioned in the Declaration, ECOWAS must ensure that the regional thematic working group on key populations is operational and functional. WAHO must support the implementation of the commitments and provide technical support to national and regional initiatives for these populations.

"strengthen strategic knowledge or information necessary to plan interventions for key populations and monitor progress towards the attainment of objectives," just 38 out of 103 (37%) RCTO-monitored facilities record data for at least one key population. Without adequate data on populations most affected by the HIV epidemic, it will not be possible for countries to effectively monitor progress against the 90-90-90 targets.

#### FIGURE 20. Key and Vulnerable Populations Reached Along the Cascade, as a Proportion of All People Reached at RCTO-WA Health Facilities (April-June 2018)63



Where health facilities do record this data, key gaps along the cascade are highlighted for key populations, particularly for linkage to care and treatment for those who are HIV-positive (Figure 20). 16% of all people who tested HIV-positive at the RCTO-WA facilities between April and June 2018 were MSM, sex workers, PWID and young people age 15-24. Yet, by June 2018, these groups made up just 7% of PLHIV on ART at the same facilities. These data highlight a disproportionate barrier to accessing treatment

for key and vulnerable populations living with HIV. Navigation into care may be particularly challenging for key and vulnerable populations for a multitude of reasons.

Sub-analyses of RCTO-WA qualitative data show that key and vulnerable populations have different reasons for not accessing ART than the general population (recall Figure 12). Among 13 focus group discussions with young people, issues of confidentiality and privacy



## **ADVOCACY ALERT**

Enhance linkage to—and retention in—care and treatment, especially for key and vulnerable populations

RCTO-WA data show that a guarter of people who test positive at RCTO-WA facilities are key and vulnerable populations but these groups make up fewer than one in ten PLHIV on ART. The UNAIDS West and Central Africa Catch-Up Plan evaluation must include age and population-disaggregated data and policy recommendations for increasing treatment initiation among key populations and

youth. Key populations networks and youth organizations must provide peer navigation for people who test positive for HIV and require support to be linked to facilities for treatment initiation.

emerge as a top reason for not accessing ART. Among 19 focus group discussions held with MSM, sex workers and PWID, fear of stigma and discrimination emerged as a key reason.

These human rights-related barriers must be addressed to improve ART initiation among key and vulnerable populations. The Dakar Declaration includes important commitments to invest in stigma reduction programs,

## **ADVOCACY ALERT**

plans

RCTO-WA data show that key and vulnerable populations face distinct human rights-related barriers to treatment initiation, including fear of stigma and discrimination and concerns about confidentiality and privacy. ECOWAS must

finalize a new HIV and AIDS Regional Strategic Plan for the period 2017-2022 and ensure that upholding the human rights of PLHIV and key population is a key strategic objective. ECOWAS must also enforce the Dakar Declaration, ensuring countries follow through on their commitments to invest in stigma reduction programs, including training individual health care providers, regulators and administrators, and organizing information and dialogue meetings between beneficiaries and providers.

### FIGURE 21. Young People Reached Along the Cascade, by Sex (March-June 2018)<sup>64</sup>



including training individual health care providers, regulators and administrators, and organizing information and dialogue meetings between beneficiaries and providers.

Further inequities are revealed by analyzing access to services along the cascade for young people age 15-24 years, disaggregated by sex (Figure 21).

## Include objectives to promote and protect human rights of PLHIV and key populations in costed HIV strategic

At every step along the cascade, young men face disproportionate barriers to access. At RCTO-WA health facilities, young women are about twice as likely to access services compared to young men. This may speak to the (in)appropriateness of service provision for young men. Health facilities may cater predominantly to pregnant women, or there may be few male service providers who help young men feel comfortable.



## **ADVOCACY ALERT**

Ensure health services are gender-sensitive to remove gender-related barriers and increase access for young men age 15-24

RCTO-WA data show that there are gender-related barriers to access, with young men about half as likely to access HIV services along the cascade compared to young women. Ministries of Health must ensure health workers are adequately trained and supported to deliver gender-sensitive services, especially for young

men. ECOWAS and WAHO must review and update the Dakar Declaration, which is currently completely silent on gender.

## GHANA

The host of the national CTO in Ghana, NAP+, along with the members of the Community Consultative Group (CCG), have used the CTO data and analysis to help mitigate HIV-related stigma and discrimination in the community. Using CTO reports as leverage, and using the multi-stakeholder nature of the CCG as an entry point, NAP+ and some CCG members paid visits to Imams, women's groups and Chiefs in Tamale. During these visits, NAP+ and CCG members presented their data and analysis around appropriateness of services. This worked to open up a dialogue with community leaders and gatekeepers around ways of reducing human rights and gender-related barriers to access HIV and other health services, especially for key populations and young people.

New prevention technologies such as PrEP, aimed primarily at key and vulnerable populations, appear grossly under-utilized in the region. Just one health RCTO-WA health facility (in Togo) reports any PrEP provision, reaching 99 MSM by June 2018. Registration of generic PrEP is planned in Côte d'Ivoire and pending in Senegal, with demonstration projects ongoing in Benin, Côte d'Ivoire, Mali and Togo.<sup>65</sup> Rollout of PrEP to key and vulnerable populations will improve the appropriateness of services provided to these groups.

## **EVIDENCE-INFORMED ACTION** ITPC's Advocacy Plan

From 23-24 October 2018, the RAB for the RCTO-WA met in Côte d'Ivoire to review the first year of data presented in this paper, and provide a critical steer on the key advocacy messages to be pushed in 2019. The RAB drafted a prioritized advocacy plan, with the top three advocacy messages for each of the 90-90-90 targets (Table 7). While these advocacy messages have been presented throughout this paper, along with additional advocacy alerts, the top priority messages are summarized here.

#### TABLE 7. ITPC's Summary Advocacy Plan

ADVOCACY PRIORITY		
By 2020, 90% of people living with HIV will know		
Expand the availability of non-facility-based HIV testing options, including community-led and community- based HTS	<ul> <li>WAHO must targeted and screening to</li> <li>Ministries of I targeted com youth, and ke</li> <li>Communities guided by the projects.</li> </ul>	
Intensify HIV communication and awareness campaigns to increase demand for HTS	<ul> <li>UNAIDS RST strategize on Based on the with common</li> <li>WAHO must national HTS populations.</li> </ul>	
Include objectives to promote and protect human rights of PLHIV and key populations in costed HIV strategic plans	<ul> <li>ECOWAS mu period 2017- key populatic</li> <li>ECOWAS mu strategic know and monitor</li> </ul>	

The advocacy plan is intended to be a living document, which will be updated and refined in an ongoing manner throughout 2019. A more detailed plan is currently being developed by ITPC, with time-bound milestones, roles and responsibilities, and indicators to measure success.

#### **KEY MESSAGES**

#### w their status

issue guidance on how to make community-based HTS I tailored to high-risk populations, and integrated with TB find the missing people with TB.

Health must update their HIV testing guidelines to prioritize nmunity-based HTS, especially led by community organizations, ey populations networks.

s must push for HIV self-testing to be made readily available, ne anticipated research results from ongoing multi-country pilot

must convene a regional meeting of key stakeholders to how to address the bottleneck in the cascade around HTS. outcomes, UNAIDS RST must implement a regional campaign, language and standardized messaging.

fund Ministries of Health and National AIDS Councils to launch campaigns, particularly targeted at key and vulnerable

ust finalize a new HIV and AIDS Regional Strategic Plan for the -2022 and ensure that upholding the human rights of PLHIV and on is a key strategic objective.

ust enforce the Dakar Declaration, ensuring countries strengthen wledge or information to plan interventions for key populations progress.

ADVOCACY PRIORITY	KEY MESSAGES	
By 2020, 90% of people living with HIV who know their status will be receiving sustained ART		
Improve communication along the supply chain to prevent stock-outs of antiretrovirals	<ul> <li>JURTA must standardize inventory management tools.</li> <li>Ministries of Health must work with health facilities, central medical stores, and communities, to identify communication barriers between actors along the supply chain.</li> <li>Countries must develop and implement multi-stakeholder communication frameworks to improve quantification, orders and deliveries of medicines along the supply chain.</li> </ul>	
Enhance linkage to—and retention in—care and treatment, especially for key and vulnerable populations	<ul> <li>The UNAIDS WCA Catch Up Plan evaluation must include age and population-disaggregated data and policy recommendations for increasing treatment initiation among key populations and youth.</li> <li>Key populations networks and youth organizations must provide peer navigation for people who test positive for HIV and require support to be linked to facilities for treatment initiation.</li> </ul>	
Strengthen community systems and responses to support the roll out of differentiated service delivery (DSD)	<ul> <li>WAHO must issue normative regional guidance on DSD including standardized information on longer refills for stable patients and community-based ART options.</li> <li>UNAIDS RST must convene key stakeholders to agree on consistent community-friendly messaging around U=U in the context of DSD.</li> <li>Ministries of Health must ensure that national DSD policies are adhered to by facilities.</li> </ul>	
By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression		
Increase funding to ensure the availability of adequate viral load testing machines and laboratory supplies	<ul> <li>AIDS Watch Africa must hold countries accountable for their Abuja Declaration commitments on health spending, ensuring Ministries of Finance provide Ministries of Health with adequate budget for viral load machines, lab reagents and maintenance plans.</li> <li>Country Coordinating Mechanisms (CCMs) must include additional viral load testing machines, including OPP technology, in their Global Fund proposals for the 2020-2022 funding cycle.</li> </ul>	
Enhance knowledge among PLHIV and healthcare workers to increase demand for high quality viral load testing services	<ul> <li>People living with HIV must have up-to-date health and treatment education, including knowledge of viral load testing guidelines about when and how often they are entitled to a viral load test.</li> <li>Health centers must train their staff on viral load monitoring, and provide supportive supervision to ensure providers are conducting viral load testing at the right time.</li> </ul>	
Ensure effective treatment monitoring through acceptable turn-around times for viral load test results	<ul> <li>WAHO must support countries to conduct HIV drug-resistance surveys and to collect and analyze early warning indicators.</li> <li>Laboratories must batch and streamline samples, sending timely results back to facilities.</li> <li>Health care providers must notify the client of their test result as soon as it is received from the laboratory.</li> </ul>	

## **FUTURE POSSIBILITIES** Sustaining Community-led Action

Since its launch in February 2017, the RCTO-WA has made remarkable strides. Eleven national CTOs have been established, trained, and supported to regularly collect and validate quantitative and qualitative data from 103 health facilities. The RCTO-WA has synthesized and analyzed a year's worth of data, highlighting the most pressing issues in the region and pushing the advocacy agenda forward.

None of this would be possible without strong community systems, including networks of PLHIV, to collect, track, analyze, and feedback the data for targeted advocacy and action. The

## **ADVOCACY ALERT** Sustain investments in the RCTO-WA to continue watching what matters and holding governments accountable for commitments to treatment access

The value of the RCTO-WA to collect, track, analyze and feedback data on treatment access in the region is clear. The data presented in this paper would not exist without the RCTO-WA, and the advocacy agenda would be less clear. Achieving the 90-90-90 targets would be less likely. Funding partners must

continue to invest in the RCTO-WA as a critical accountability mechanism for improving treatment access in the West Africa region. Governments and health facilities must continue to partner with the national PLHIV networks, sharing their data to advance a common goal.

Going forward, the RCTO-WA has the potential to augment and deepen its impact in a number of important ways, given the right partnerships and levels of investment. Based on the RCTO-WA's demonstrated successes. this section provides some strategic future possibilities for even stronger community systems in West Africa.



relationships among the PLHIV networks, the health facilities, and the national and regional decision-makers, are critical to foster and maintain. These relationships ensure that there is accountability for commitments to treatment access, and work to strengthen linkages between facility-provided services and improving community demand and access.

To achieve the 90-90-90 targets, ongoing community monitoring is critical. Sustaining the investments in community action is imperative. Without transparency, there can be no accountability.

**Going beyond health facilities.** At present, the RCTO-WA collects and analyzes data from people who are already accessing services at health facilities. This sampling bias may be significantly underestimating barriers to access in the region. It would be beneficial for the RCTO-WA to collect complementary community data from people who have not (yet) sought care. This would enable a better understanding of the reasons for non-utility of services or

non-retention in care. People could be sampled through the networks of PLHIV, or through networks of key populations. This approach would also enhance the RCTO-WA's ability to assess demand for, and barriers to, prevention-related services.

**Understanding the rural context**. The

RCTO-WA is currently focused on collecting data from health facilities in high-density urban locations. Of the 103 RCTO-monitored facilities, just 9 are outside of capital cities (3 in Sabi, Gambia; 6 in Zwedru, Liberia). While this is important for the RCTO-WA to have a significant number of PLHIV in its sample, and for efficiencies in data collection, it means the RCTO-WA is not currently capturing the reality of health service delivery in less-resourced rural areas of the region. Access to, and quality of, services is likely over-estimated in the RCTO-WA sample, compared to the rural context. Expanding the RCTO-WA health facility sample to include more non-urban sites would enable comparative analysis of urban versus rural service access and quality.

- **Real-time data analysis.** The reality of the West African context is that paper-based patient record systems are used at the majority of health facilities. The RCTO-WA transcribes this data into an electronic system. This is time consuming and renders the CTOs more prone to data entry errors. If the RCTO-WA were equipped with electronic, portable data capturing devices (tablets or smartphones) the CTOs would be able to generate real-time data analysis. This would strengthen their own analysis, but also improve the CTOs' ability to provide regular and timely feedback to communities of PLHIV as well as to the facilities the monitor. ITPC's treatment observatory in Zimbabwe is using this preferred model, capturing data on tablets, uploading it to a centralized databased, and conducting realtime analysis and feedback.
- **Creating demand for services.** The data collected by the RCTO-WA is useful for holding facilities accountability for improved service delivery. Additional and important uses are to inform demand creation efforts led by civil society and community-based organizations as well as networks of PLHIV and key population. It has been argued that the missing "A" awareness—must be applied to develop, implement, and evaluate health care services and access more generally.<sup>66</sup> RCTO-WA data show that demand creation for HIV testing services and for viral load testing services are critical gaps in the 90-90-90 cascade. ITPC's successful community-led demand creation model can be used to expand service uptake in the region by improving health and treatment education, viral load guidelines, U=U, differentiated services delivery and patients' rights.
- Integrating tuberculosis. In the wake of the 2018 UN Political Declaration on TB, enhanced community monitoring is critical for finding the missing people with TB, integrating TB efforts more fully into all relevant health services, and increasing access to TB services. The RCTO-WA is well-placed to contribute towards the accountability framework of the Declaration, with the potential to add additional indicators to its data collection tools and track the uptake and quality of TB services. Those involved in the implementation and monitoring of the Declaration should see the RCTO-WA as a vital accountability resource.
- Implementation through partnerships. The Global Fund's Implementation through Partnership (ITP) project (including key partners like WHO) is enabling 20 targeted countries to remove hindrances blocking the absorption and use of grants. Five RCTO-WA countries (Benin, Côte d'Ivoire, Ghana, Guinea and Mali) are part of this initiative. RCTO-WA data can help this initiative by identifying key implementation bottlenecks and offering community-identified solutions to improve the utilization of grants and the achievement of

targets in country performance frameworks. Partnerships with the ITP team at the Global Fund, and with these priority countries, is a strategic opportunity for the RCTO-WA.

- Collecting and analyzing early warning (proxy) indicators for HIV drug-resistance. Analyses warn of high (7.2%) prevalence of pretreatment drug resistance in Western and Central Africa.<sup>67</sup> The WHO recommends standardized surveys to assess the situation, but limited funds and a lack of available technical assistance means these are not taking place. The RCTO-WA can play an important role in collecting and assessing proxy early warning indicators, in the absence of comprehensive national surveys. Partnerships with WAHO, WHO and national governments are needed for the RCTO-WA to perform this important function.
- Assess the impact of community monitoring on improved health service **delivery.** As the RCTO-WA continues to collect and analyze data, it is expected that the community monitoring initiative will have a positive effect on improved health service delivery and improved government accountability. As implementation of the project progresses, it will be important to assess the impact of the RCTO-WA as a community monitoring initiative. Such an assessment will grow the evidence base for strengthening community systems and responses, and will further demonstrate to governments and other national and regional decision-makers that a strong civil society is valuable partner in the HIV response.
- Looking ahead to 95-95-95. 2020 is not the finish line. We must not be slowing down as we approach the Fast-Track deadline, but rather, speeding up towards the next set of targets. We should already be looking ahead to 95-95-95 (by 2025), advocating for these targets to be adopted in national strategic plans, to be budgeted for by Ministries of Finance, and to be monitored by

communities. The RCTO-WA is well-placed to drive this advocacy agenda forward in the region. With key partners like UNAIDS, the RCTO-WA can help kick-start the transition from the Catch-Up Plan to achieving the 2025 targets.

Measuring and improving quality of life for PLHIV. Achieving the Fast-Track treatment targets must be done in the context of good quality care and a high quality of life for PLHIV. This paper has drawn attention to quality of care as a key barrier to effective treatment in the region. But quality of life matters even if a person is accessing ART and has achieved viral suppression. Including dimensions of well-being and wider social, cultural and economic rights are important for helping people maintain their treatment in the long-term and helping people deal with the new era of issues brought by 'ageing with HIV'.<sup>68</sup> The RCTO-WA has the potential to measure and advocate for improved quality of life for PLHIV, sustaining gains made in the longer term—towards ending AIDS by 2030.

## **ENDNOTES**

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Equatorial Guinea, Liberia, and Gabon have planned test-and-treat rollout for later in 2018/early 2019. Togo is the only country in the region with no planned year for implementation. ND is available for Cabe Verde, Chad, Mauritania or Western Sahara. (Source: World Health Organization (2018). WHO HIV Policy Adoption and Implementation Status in Countries: Fact Sheet. July 2018. Online at http://apps.who.int/iris/bitstream/ handle/10665/275468/WHO-CDS-HIV-18.21-eng. pdf?ua=1)

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