

Why We Must Watch What Matters:

INITIAL FINDINGS FROM THE REGIONAL
COMMUNITY TREATMENT OBSERVATORY IN WEST AFRICA



ABOUT RCTO-WA

The Regional Community Treatment Observatory in West Africa (RCTO-WA) is a consortium project led by the International Treatment Preparedness Coalition (ITPC) and ITPC West Africa. The project works to increase access to optimal HIV treatment in 11 West African countries through the systematic monitoring of HIV care and services.

A community treatment observatory is a mechanism that systematically collects data to monitor trends on treatment access along the HIV Cascade to be used for targeted action. Monitoring of health systems by communities increases government accountability and informs targeted advocacy actions that can improve HIV treatment, particularly for key populations.

ABOUT THIS REPORT

To establish a reference for comparative analysis over the course of the three-year project, a baseline study was conducted in each of the 11 project countries. The purpose of the study was to (1) identify key barriers to access of HIV, prevention, care, and treatment services, and (2) document existing capacity of national PLHIV networks. This report presents key findings from this study.

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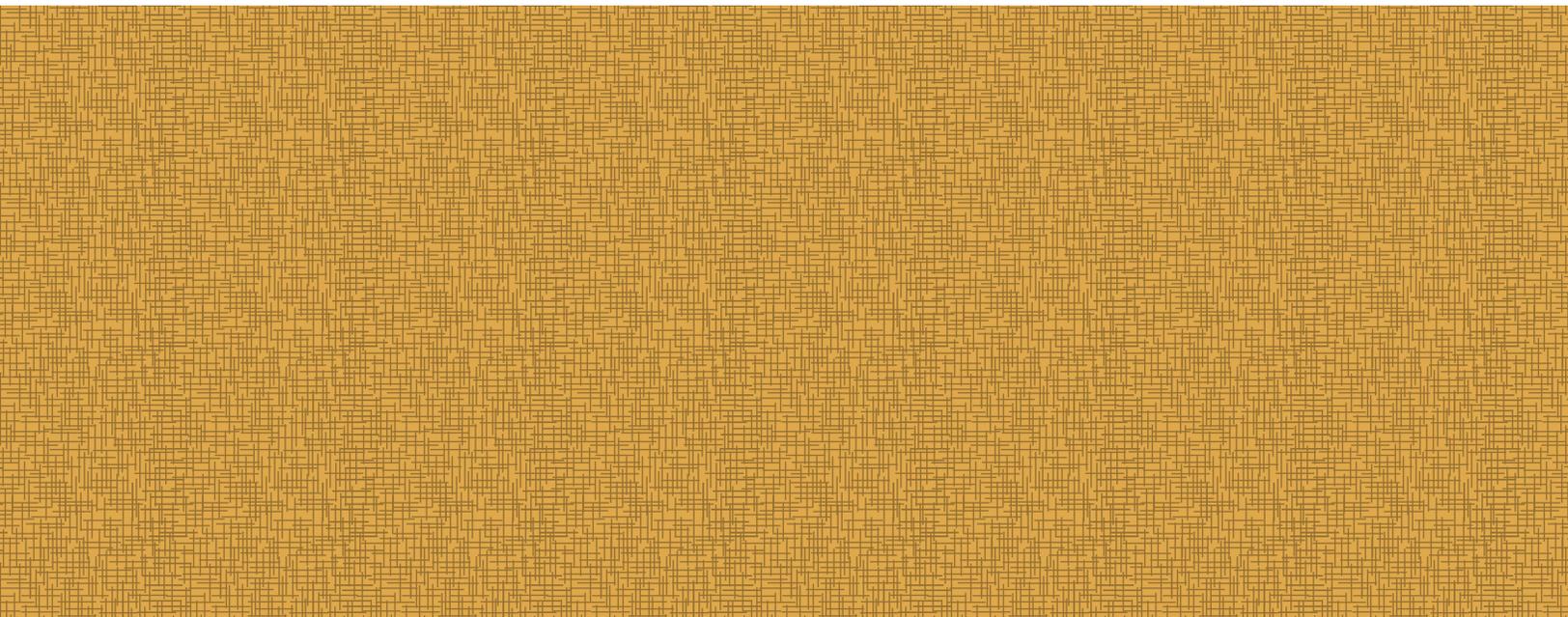
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INTRODUCTION

BACKGROUND AND CONTEXT

Community based monitoring offers the potential of increasing domestic oversight and advocacy for improvements to HIV treatment, particularly as it affects key populations. Affected communities consume most antiretroviral therapy (ART) services but usually lack the necessary capacity and information needed to participate meaningfully in decision-making that shapes treatment programs that directly impact their lives.

Having monitored repeated stock outs of antiretrovirals (ARVs) in West Africa through its treatment observatories, the International Treatment Preparedness Coalition (ITPC) and ITPC West Africa submitted an Expression of Interest (EOI) to the Global Fund in April 2015. The proposal intended to provide catalytic support to centralize and standardize treatment access data, through the creation of treatment observatories in 11 West African countries, in order to improve regional advocacy for ART access.

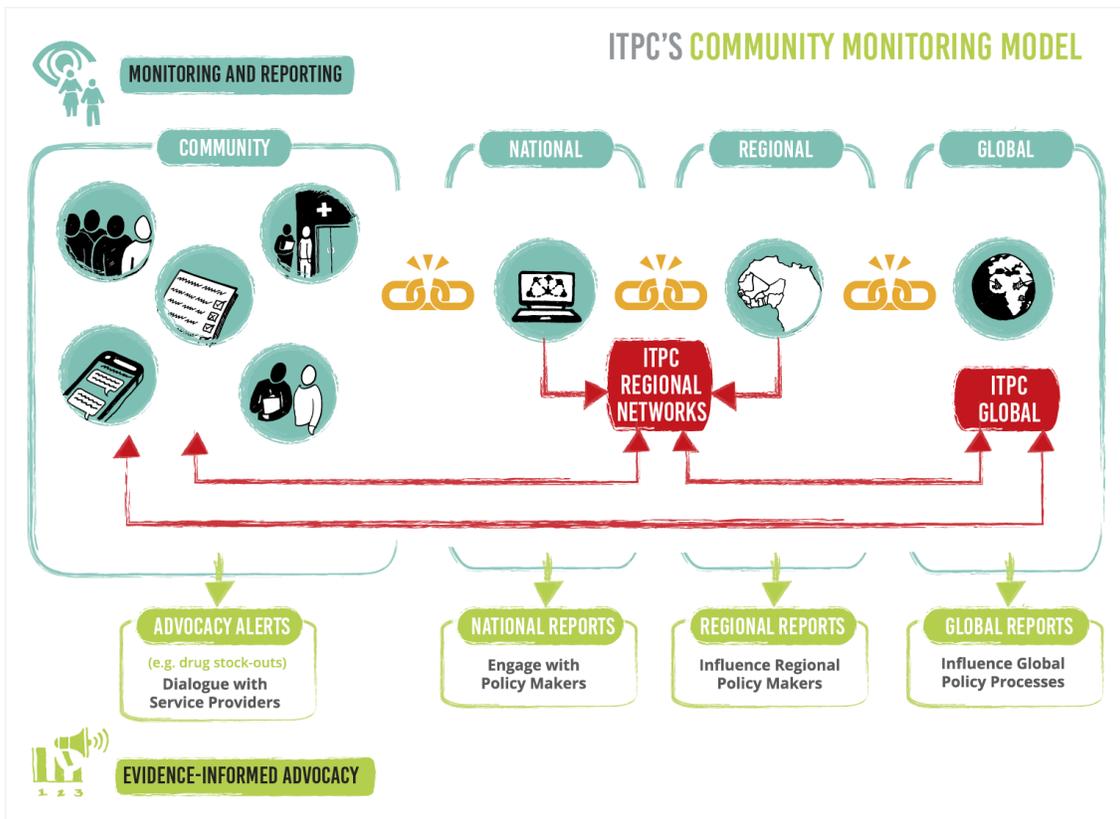
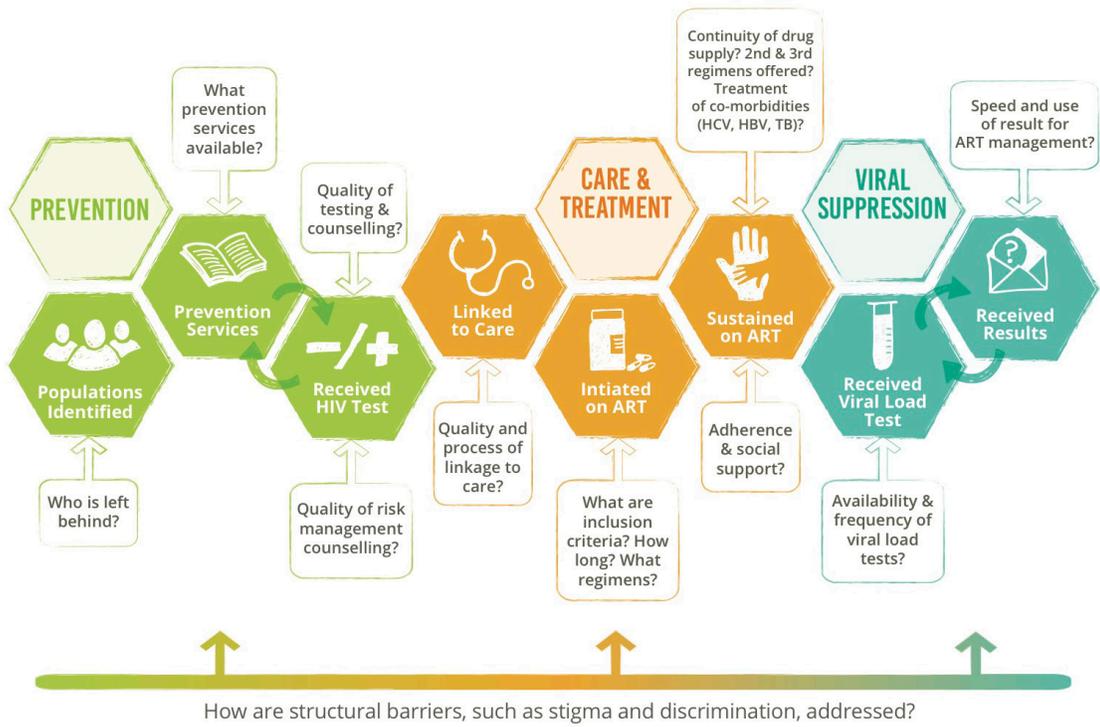
In 2016, the Global Fund approved a 3-year grant (January 2017 and December 2019) to support this work and the Regional Community Treatment Observatory in West Africa (RCTO-WA) was born.

The RCTO-WA is a consortium project empowering networks of people living with HIV to systematically collect and analyze qualitative and quantitative data on barriers to access. The goal is 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.

A community treatment observatory is a mechanism that systematically collects data to monitor trends on treatment access along the HIV Cascade to be used for targeted action. Monitoring of health systems by communities increases government accountability and informs targeted advocacy actions that can improve HIV treatment, particularly for key populations.

ITPC COMMUNITY MONITORING

Along the HIV Continuum of Prevention, Care and Treatment



STUDY GOALS AND OBJECTIVES

To establish a reference point and assess the results of the RCTO-WA project implementation activities, the baseline study sought to document the current status in the countries, along HIV prevention, treatment and care indicators, as well as the existing capacity of national PLHIV networks (referred to as

sub-recipients). The project focuses on five populations – men who have sex with men (MSM), sex workers, people who inject drugs (PWID), pregnant women and young people—who are at greater risk of HIV infection and face greater challenges to accessing HIV prevention and treatment services.

STUDY METHODOLOGY

A dual approach was adopted for this baseline study:

DESK REVIEW: To assess the current level of access to services across the HIV Continuum of Prevention, Care and Treatment (CoPCT), in-country, regional and national health reports were reviewed. This included analysis of regional health data reports from the West Africa Health Organization (WAHO)/ Economic Community of West Africa States (ECOWAS), national health data, and national HIV strategies and reports from the Global Fund/ Country Coordinating Mechanism (CCM), the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) and UNAIDS. Organizational

documents and capacity assessments provided by the national PLHIV networks were also assessed to ascertain current capacity in advocacy and community monitoring.

QUANTITATIVE AND QUALITATIVE DATA COLLECTION: To supplement and validate the desk review findings, sub-recipients in each of the 11 countries collected quantitative data at previously identified and selected sites. ITPC monitoring and evaluation staff and an external consultant later carried out key informant interviews and focus group discussions to collect qualitative data. Ethical clearance was obtained in 5 countries, as needed.

TABLE 1
Data sites targeted for quantitative and qualitative data collection

Number of data sites	36
Number of key informant interviews (KIIs)	114
Number of focus group discussion (FGDs) conducted	22

INITIAL FINDINGS: WHAT DID THE DATA REVEAL?

1. HIV testing services are available, but more must be done to link to HIV treatment and care.

Across the surveyed countries, rapid HIV testing is available and offered at health sites; test results are provided within 15 minutes. Except for Guinea-Conakry and The Gambia, ART is initiated for those who test positive

according to the 'Test and Treat' protocol. In The Gambia, ART is initiated when CD4 is equal to or less than 300 copies/ml, and in Guinea-Conakry, when CD4 count is less than 500 copies/ml. Pregnant women and female PWID, who are already linked to health services for other conditions, are more likely to be connected to HIV care and treatment services, if needed.

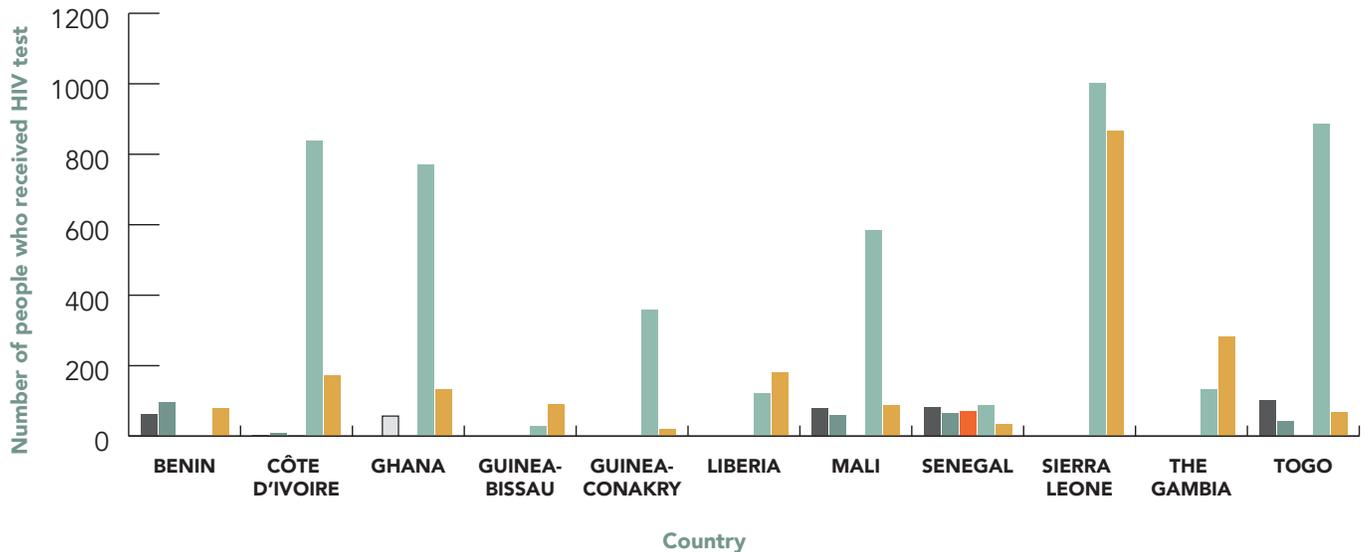
TABLE 2
Latest national level data on HIV testing in MSM, Sex Workers, PWID¹ from UNAIDS

COUNTRY	HIV TESTING AMONG MSM	HIV TESTING AMONG SEX WORKERS	HIV TESTING AMONG PWID
BENIN	66.5% (2015)	76% (2015)	93.5% (2015)
CÔTE D'IVOIRE	77.2% (2015)	76.4% (2015)	22.8% (2015)
GHANA	26.3% (2014)	66.7% (2013)	No Data
GUINEA	45.9% (2014)	94.4% (2015)	No Data
GUINEA-BISSAU	31.7% (2014)	93.7% (2013)	No Data
LIBERIA	44.4% (2015)	No Data	27.9% (2015)
MALI	99.6% (2015)	70.9% (2015)	No Data
SENEGAL	41.9% (2015)	66.4% (2015)	9.1% (2015)
SIERRA LEONE	41.2% (2015)	61.1% (2015)	13.0% (2015)
THE GAMBIA	20.0% (2013)	No Data	No Data
TOGO	83.9% (2015)	74% (2015)	31.6% (2015)

¹ Data collected from UNAIDS AIDSinfo Online Database

FIGURE 1

Number of people who receive an HIV test per country disaggregated by key population group from site data collection (June-July 2017).



MSM SW PWID PREGNANT WOMAN YOUTH

COUNTRY	MSM	SW	PWID	PREGNANT WOMAN	YOUTH
BENIN	62	95			79
CÔTE D'IVOIRE	4	10	0	838	173
GHANA		57		770	132
GUINEA-BISSAU					
GUINEA-CONAKRY				360	21
LIBERIA					
MALI	79	59		584	88
SENEGAL	83	64	72	87	33
SIERRA LEONE				1001	866
THE GAMBIA				134	284
TOGO	102	42		886	68

*Blank cells signify that data was not available

While data available at country level (Table 2) and data collected at various sites in-country (Figure 1) are not directly comparable, it's clear that there is a lack of disaggregated data and is not representative of all key population groups.

2. Stigma and discrimination remain a major barrier to HIV prevention and treatment services.

Qualitative interviews revealed that HIV-related stigma and discrimination is a major issue for all five target populations in the region, evident in multiple forms.

Unsurprisingly, the fear of HIV-related stigma emerged as a universal barrier to HIV testing among all populations. The repercussions of obtaining a positive HIV test result was enough to deter many from going in for a test. Fear of rejection by family and loved ones was particularly strong, with some expressing the desire to not even know their status rather than deal with the impact. Married and/or pregnant women faced an additional burden: gender norms and local customs often require women to obtain approval from their husbands in order to get tested. In Guinea-Conakry, women reported being forbidden from getting an HIV test by their husbands.

Similarly, HIV-related stigma and discrimination was reported as a direct barrier to accessing treatment. Respondents indicated that the fear of their sero-status being known caused them to miss appointments and forced them to choose a health center located further away to prevent them from being seen or recognized. Adherence is also affected, as the fear of family or husbands finding out their status and the resulting rejection caused some to reportedly stop taking their ARVs.

Stigmatizing attitudes from healthcare personnel also kept respondents from accessing care. MSM in Sierra Leone, Liberia, and The Gambia, particularly those perceived as "feminized," preferred to stay away from

"In my country, a PLHIV is considered like a bandit. There's a lot of discrimination."

– Respondent in Guinea-Bissau

health centers for fear of being discriminated against as a result of their sexual orientation. Similarly, Gambian sex workers dressed differently for fear of their occupation being known and being discriminated against. MSM in Guinea Bissau, The Gambia and Ivory Coast raised concerns around confidentiality, fearing that their personal information would be made known outside the health centre, leading to further stigma and discrimination.

3. Economic considerations significantly impact access to HIV prevention and treatment services.

The cost of transport to local health centres was a barrier raised by all populations in all countries surveyed. This was particularly an issue for those living in rural or isolated areas, which are less serviced. As raised by MSM in The Gambia and by youth, pregnant women and MSM in Côte d'Ivoire, the cost of visiting a health centre for testing or treatment was particularly prohibitive, when they attend a health centre farther from home to avoid being recognized.

Beyond the cost of transport, the direct cost of ARVs and related needs were prohibitive. The absence of freely available nutritional support was cited as a reason to not attend health centres, as respondents reported having to decide between spending money on medications or food.

Economic costs also represented an additional hindrance for pregnant women and youth who had to depend on their husbands or parents/family members to provide the funds to visit a health centres.

“It is a challenge having access to ARVs while also feeling hungry but not being able to afford food.”

– Respondent in Sierra Leone

4. Substantial knowledge gaps and misconceptions about HIV still exist

Across all the countries, there were clear knowledge gaps about HIV among the key and vulnerable populations. For example, in Benin, Guinea-Conakry and Senegal, respondents confused HIV testing with blood donation. MSM in Togo and sex workers respondents in both Togo and Cote d’Ivoire, indicated that they were wary of HIV tests, fearing that their blood would be sold. As expressed by youth respondents in Togo and PWID in Senegal, an HIV test is not required unless one is evidently thin or unwell. MSM in Côte d’Ivoire and sex workers in Sierra Leone did not believe in the existence of HIV and therefore saw no value in getting tested.

Similar misconceptions were prevalent around HIV treatment and care. In The Gambia, Ghana and Togo, respondents indicated that they would turn to traditional medicine to treat HIV. Even among those diagnosed with HIV, many refused to or did not start treatment because of a lack of visible symptoms or the feeling of being “unwell”. Pregnant women in Ghana reported not being authorized to start treatment by their husbands because they did not look sickly. Key informant interviews and focus group discussions also revealed that knowledge and understanding about how ARVs work was lacking in all countries. Young people and MSM in Cote d’Ivoire believed that they would die regardless of whether they started ART, and people living with HIV in Sierra Leone reported that they had stopped taking their medications after feeling better after a few months on ART.

Consistently across the region, while knowledge about HIV prevention, treatment and viral suppression, was low among all populations, it was particular low among young people who lacked basic information. In fact, youth themselves in Mali expressed the need for more information on HIV testing and treatment management and living with HIV to be made available.

“There used to be more information on HIV. Now there has been some sort of loosening with younger generations.”

– MSM Respondent
in focus group discussion in Benin

5. KPs call for services tailored to their needs and ease of access.

While the thematic trends discussed thus far are applicable across all target populations, the baseline also reinforced that each population had specific needs, and tailored approaches were required to increase access to prevention and treatment services. Young people in Togo, for example, reported difficulties obtaining time off from school for medical appointments and were willing to forgo treatment rather than wait.

6. ART management remains a challenge

Stock outs of first-line ARVs were reported in Ghana, The Gambia and Cote d’Ivoire. In particular, paediatric ARVs were reportedly frequently out of stock, as were medicines for opportunistic infections. Where ARVs were available, respondents reported suffering from side-effects of medications, with direct implications on treatment adherence.

Pregnant women in Guinea-Conakry and Cote d'Ivoire indicated that they did not adhere to their treatment as prescribed because of side effects.

Treatment monitoring and viral load testing was also highlighted as a challenge in the region. With the exception of Mali, Guinea-Conakry and Togo where respondents were familiar with routine viral load testing (RVLT), the majority of people living with HIV surveyed had no knowledge of viral load testing. The data reflected this, highlighting substantial challenges in accessing treatment monitoring services – both in receiving a viral load test and subsequent results (Table 4). Further data collection will help clarify whether this is due to the lack of knowledge, the lack of available services, or both. Most countries require blood samples to be sent to a centralized national laboratory, resulting in delayed results. Respondents reported the average turnaround time ranged from two weeks to three months.

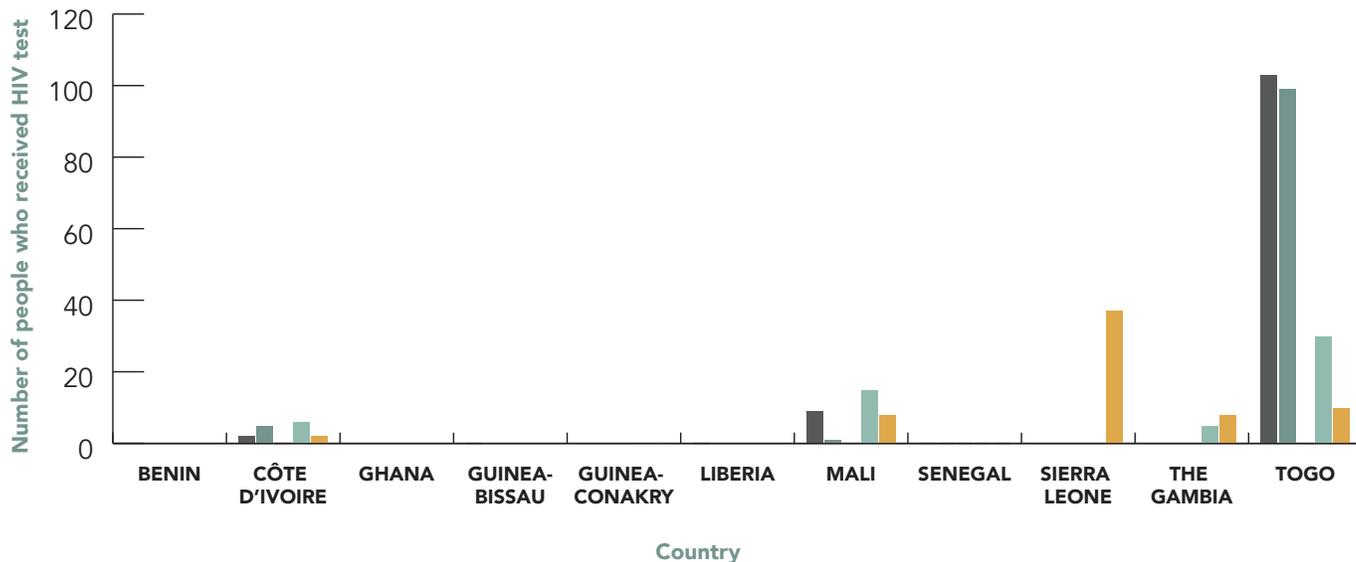


“Even if the viral load test is free, we ask patient to come at a very specific time that might not be convenient for them, or also generates additional costs.”

- Pharmacist in Senegal during an interview

FIGURE 2

Number of people who receive an a viral load test per country disaggregated by key population group from site data collection (June-July 2017).



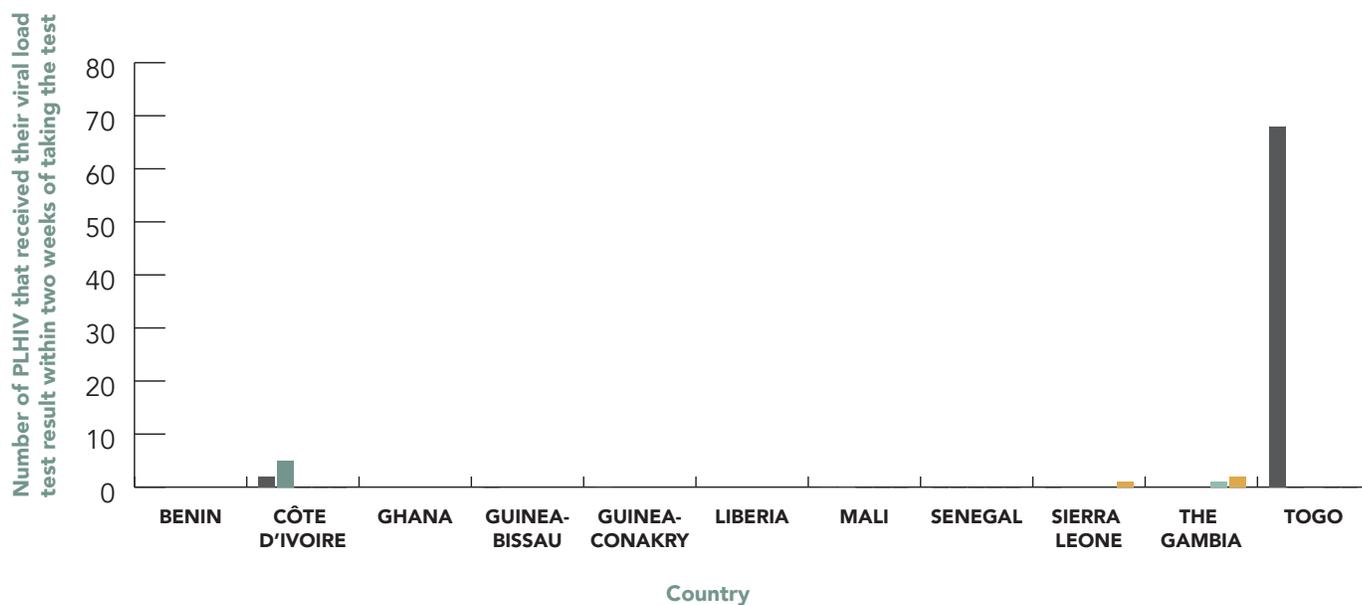
MSM
 SW
 PWID
 PREGNANT WOMAN
 YOUTH

COUNTRY	KEY POPULATION GROUP				
	MSM	SW	PWID	Pregnant Woman	Youth
BENIN					
CÔTE D'IVOIRE	2	5	0	6	2
GHANA					
GUINEA-BISSAU					
GUINEA-CONAKRY				0	0
LIBERIA					
MALI	9	1		15	8
SENEGAL	0	0	0	0	0
SIERRA LEONE					37
THE GAMBIA				5	8
TOGO	103	99		30	10

*Blank cells signify that data was not available

FIGURE 3

Number of people who receive their corresponding viral load test results per country disaggregated by key population group from site data collection (June-July 2017).



MSM
 SW
 PWID
 PREGNANT WOMAN
 YOUTH

COUNTRY	KEY POPULATION GROUP				
	MSM	SW	PWID	Pregnant Woman	Youth
BENIN					
CÔTE D'IVOIRE	2	5	0	0	0
GHANA					
GUINEA-BISSAU					
GUINEA-CONAKRY				0	0
LIBERIA					
MALI	0	0		0	0
SENEGAL	0	0	0	0	0
SIERRA LEONE					1
THE GAMBIA				1	2
TOGO	68	0		0	0

*Blank cells signify that data was not available

CONCLUSION & NEXT STEPS

Key populations continue to face substantial barriers in accessing quality HIV services. **The data and initial findings of the RCTO-WA outlined here reinforce the known experiences of communities in West Africa.** Stigma and discrimination, lack of knowledge and awareness on basic science of HIV, cost, and procurement failures prevent key populations from accessing the prevention and treatment services they want and need.

What is most notable is the data, or lack thereof, on access to services for specific populations. Health reports at national and regional level continue to fail to disaggregate key population-specific data. While some groups – e.g. pregnant women – are better captured by the health system, others remain

unseen (as seen illustrated in Tables 3 and 4). Similarly, comprehensive data on stock outs and access to treatment monitoring is clearly lacking. Limitations in routine viral load testing also has grave implications in reaching better treatment outcomes, and achieving viral suppression.

Over the course of 2018-2019, the RCTO-WA, through 11 networks of PLHIV in West Africa, will continue to systematically monitor and analyze quantitative and qualitative data on barriers to access of HIV prevention, treatment and care services. Periodic reports and comparative analyses will be published and made widely available at **WatchWhatMatters.org**.

