The Community Treatment Observatory (CTO) Model Explained

HOW COMMUNITIES CAN COLLECT AND ANALYZE HEALTH DATA TO ENSURE ACCOUNTABILITY AND DRIVE CHANGE

Watch What Matters | REGIONAL COMMUNITY TREATMENT OBSERVATORY West Africa

ITPC INTERNATIONAL TREATMENT PREPAREDNESS COALITION

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 that gathers data on access to and quality of HIV treatment globally. It fulfills one of ITPC's core strategic objectives, to ensure that those in power remain accountable to the communities they serve.

Community monitoring of health systems increases government accountability and informs targeted advocacy actions that can improve HIV treatment, particularly for key and vulnerable 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 from Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ), ITPC formalized community treatment observatories (CTOs) 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 that it reflects the issues and questions that are most important to people living with and affected by HIV. It relies on a unique model that empowers communities to systematically, routinely collect and

analyze qualitative and quantitative data on access barriers, and use it to guide advocacy efforts and promote 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

This publication describes a model of community-led monitoring known as a community treatment observatory (CTO). It is a detailed guide for developing a CTO; it explains what a CTO is—as defined and designed by ITPC—and outlines the structure, purpose and benefits of a CTO.

It also describes how CTOs inform HIV treatment advocacy, and illustrates how they can be operationalized in various contexts, with examples from our RCTO-WA.

This publication is intended for any organization or community interested in community-led monitoring, including, but not limited to, community-based organizations, PLHIV networks, and program implementers.

FOR MORE INFORMATION

Please contact us at admin@itpcglobal.org.

CONTENTS

ACRONYMS & ABBREVIATIONS

ART   Antiretroviral therapy

ARVs   Antiretovirals

CCG   Community consultative group

CCM   Country coordinating mechanism

CSS   Community system strengthening

CTO   Community Treatment Observatory

EECA   Eastern Europe Central Asia

GIZ   Deutsche Gesellschaft für Internationale Zusammenarbeit

HIV   Human Immunodeficiency Virus

HIV CoPCT   HIV Continuum of Prevention, Care and Treatment

HMIS   Health management information systems

IEC   Independent ethics committee

IRB   Institutional review board

ITPC   International Treatment Preparedness Coalition

M & E   Monitoring and evaulation

MoH   Ministry of Health

MoU   Memorandum of understanding

MSM   Men who have sex with men

MTT   Missing the Target report series

PEP   Post-exposure prophylaxis

PLHIV   People living with HIV

PrEP   Pre-exposure prophylaxis

PWID   People who inject drugs

RCTO-WA   Regional Community Treatment Observatory in West Africa

UNAIDS   Joint United Nations Programme on HIV/AIDS

WHO   World Health Organizations

WWM   Watch What Matters

INTRODUCTION

With just over a year to go until the UNAIDS 2020 targets, we face a stark reality—there is immense inequality in treatment access among specific populations and in certain locations, despite the considerable accomplishment of delivering life-saving antiretroviral therapy (ART) to 21.7 million people, globally.[1]

More often than not, global and regional data mask national and local disparities. For example, while more than half of all people living with HIV (PLHIV) globally are accessing ART, in Liberia, just 29% of people living with HIV are accessing it. For those living outside of the capital city Monrovia, chances of accessing ART are even slimmer.[2]

In order for the world to achieve sustainable public health outcomes, progress towards HIV targets—like 90-90-90[3]—needs to be inclusive of, and responsive to data on quality of care. Yet global, regional and national data rarely include comprehensive reports on the quality of HIV services, although it fundamental to their success. People who receive poor quality care are less likely to remain engaged in HIV care and treatment, which puts them at risk for avoidable illness and death, and there is evidence that poor-quality care is a larger cause of excess mortality in lower-middle income countries than non-utilization of health care.[4]

In 2017 WHO issued *Consolidated Guidelines on Person-Centered HIV Patient Monitoring and Case Surveillance*, to support "… a progressive shift from measuring services (e.g. the number of tests performed or people on treatment) to placing people and their access to linked HIV and health services (prevention, testing, treatment and chronic care) at the centre of monitoring the health sector response to HIV."[5]

Yet observations from the field show that treatment policies and guidelines are not reliably or uniformly implemented. Factors such as human and financial resources, the quality of training that healthcare workers receive, the availability of medicines or lab tests and equipment to perform them also vary, and influence the quality of services. Although PLHIV and their communities use most of the available ART services, they frequently lack the necessary information and platforms to participate meaningfully in decision-making to the shape treatment programs that directly impact their lives.

Community-led monitoring offers the potential to increase oversight of, and advocacy for improvements to HIV services. It empowers recipients of care, civil society and community-based organizations to play a key role in collecting valuable information on both the availability and quality of treatment services, which can be used to hold health leaders accountable.

Over the last decade, the International Treatment Preparedness Coalition (ITPC) has been monitoring the scale-up of HIV services in different countries from a community perspective. We have been successful in building the capacity among treatment activists worldwide, to collect and analyze data, and to demonstrate how community-led monitoring empowers communities to offer solutions and meaningfully engage in the health system.

In this publication we describe one model of community-led monitoring known as a community treatment observatory (CTO). The purpose of this report is to explain what a community treatment observatory is, as defined and designed by ITPC, and illustrate how it is used to facilitate HIV treatment advocacy.

WHAT IS A COMMUNITY TREATMENT OBSERVATORY (CTO)?

A **community treatment observatory (CTO)** is a mechanism that systematically and routinely collects and analyzes qualitative and quantitative data. This data is used for monitoring trends along the HIV care cascade, and to inform targeted action that will improve the quality of HIV services.

In a CTO, an organized group of community members—such as a network of people living with HIV—collect data on various aspects of HIV prevention, testing, care, and treatment services. This can include, for example, indicators on the number of HIV tests conducted in a specified area, or the frequency and duration of ARV stock-outs experienced in a certain time period. Community monitoring is an ongoing process, with multiple entry points. Figure 1 shows how community monitoring can be used to assess service provision along the HIV care cascade.

Unlike other community monitoring or research mechanisms, CTOs are a **systematic** and **continuous** monitoring process. Data is collected at set intervals (e.g. monthly), and entered into a centralized database. Because data is routinely collected, CTOs can monitor trends and variations within the health system over time This allows activists to document the availability, continuity and quality of all aspects of HIV service delivery, alert procurement systems when commodities (i.e. drugs and diagnostics) reach critically low levels, and develop and issue recommendations for improvements.

After being collated and checked for quality, the data from all sites is analyzed, and the results are used to inform targeted advocacy.

A CTO can operate at district-, provincial-, national-, regional-, or global-level. Figure 2 shows how community monitoring can be coordinated across these levels, with data and evidence captured at the community level and flowing upwards, to inform advocacy at national, regional and global levels, as needed —and vice versa.

FIGURE 1
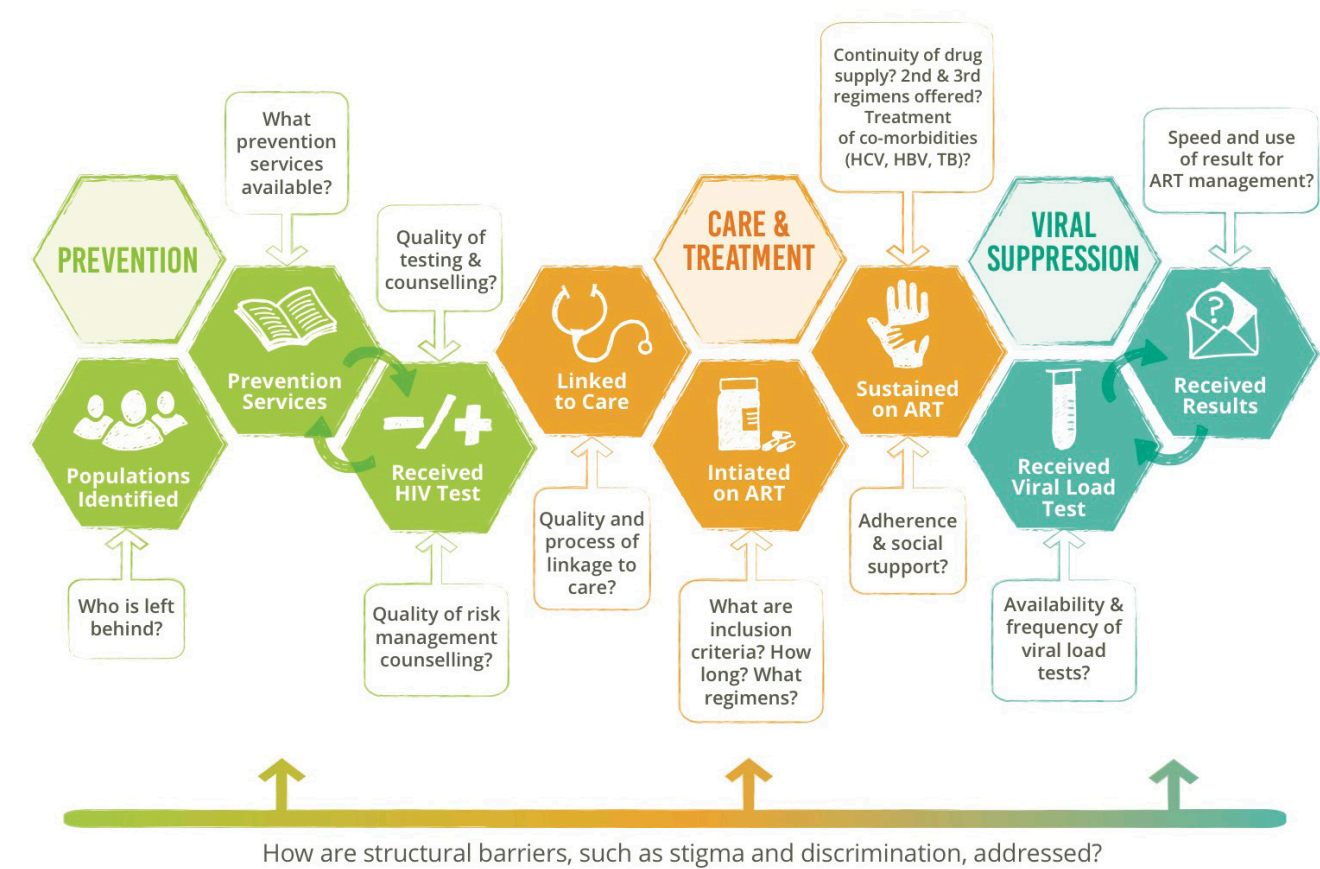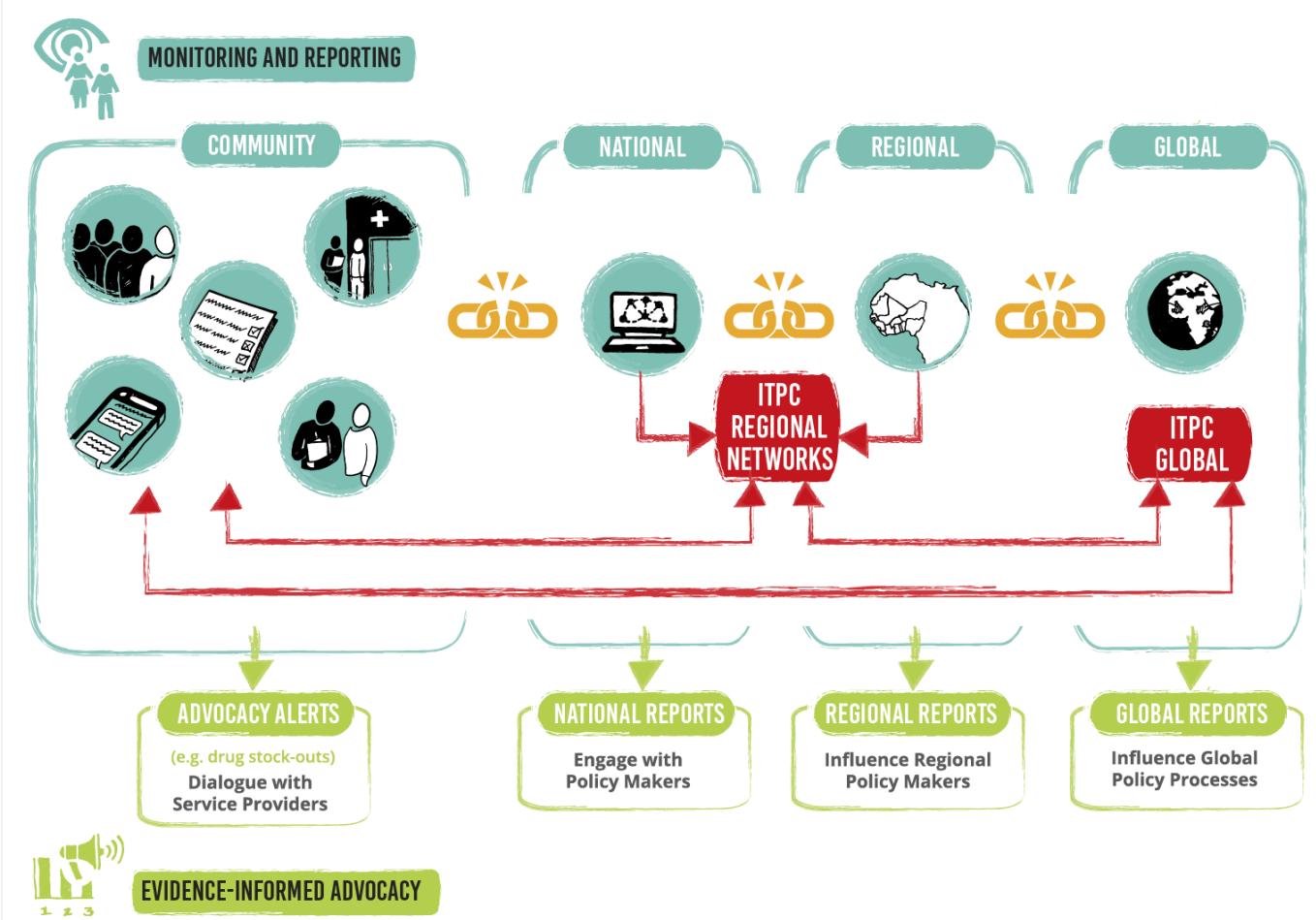**Community Monitoring Along the HIV Continuum of Prevention, Care and Treatment.**

FIGURE 2
ITPC Community Monitoring Model

WHAT DO COMMUNITY TREATMENT OBSERVATORIES MONITOR?

Community observatories can monitor aspects of any health or social justice issue.

When used within the HIV sector, CTOs monitor community-defined issues along the HIV Continuum of Prevention, Care and Treatment (CoPCT), referred to as the HIV Cascade.[6] This includes, but is not limited to, policy implementation, quality of service delivery, prevention, testing, linkage to care, enrollment, treatment, and retention.

In a CTO, data on these issues is collected through both quantitative and qualitative indicators:

- **Quantitative data** indicators measure and track numbers (e.g. number of HIV tests performed). They are collected at the health facility level and are used to provide the current picture of what services look like. While some of the quantitative data collected by a CTO can be similar to that collected by national health management information systems (HMIS), in many cases, CTOs collect data that national systems do not track (e.g. stock-out monitoring, turn-around time before test results are shared with recipients of care, disaggregation by key populations etc.).

- **Qualitative data** indicators describe and characterize the nature of a situation. They help reveal the lived realities and points of view among recipients of care and their communities. Qualitative data is collected through open-ended survey questions, interviews, and focus group discussions. National HMIS do not often track qualitative data. Therefore, qualitative data collected by a CTO provides unique insights, and explains or better characterizes issues identified by quantitative data.

Together, quantitative and qualitative data from a CTO provide the most complete picture of what is happening with service delivery along the HIV cascade—in terms of both access and quality.

Examples of quantitative and qualitative indicators that have been used in CTOs are listed in Table 1 and Table 2, respectively.

What is the Difference Between Alert Systems & Community Treatment Observatories?

Communities have been sounding the alarm on ARV stock-outs since these drugs became available to them. These alert systems - where PLHIV and peer health workers notify PLHIV networks any time a stock-out happens in their community - are a responsive platform that helps to report health system failures. Unlike alert systems, CTOs monitor a set of comprehensive indicators systematically, over time. They operate routinely, which allows communities to analyze trends in data over time, and come up with community-based, evidence-driven solutions. In many ways, CTOs build upon the foundational elements of an alert system. By engaging partners - academic institutions, community consultative groups (CCGs) and other relevant stakeholders, CTOs empower communities to robustly monitor both access to, and quality of health services, and offer solutions to key issues as they arise. In theory, over time, a highly functional CTO should reduce the number of alerts raised in a health system by identifying and addressing root-cause issues.

TABLE 1 Examples of quantitative indicators that can be collected by CTOs

AREA OF FOCUS	INDICATOR	
PREVENTION AND TESTING	1. Number of people who received an HIV test 2. Number of people who received an HIV test and know their result	3. Number of people eligible for pre-exposure prophylaxis (PrEP) who receive it 4. Number of people eligible for post-exposure prophylaxis (PEP) who receive it
CARE & TREATMENT	1. Number of PLHIV initiating ART 2. Number of PLHIV receiving ART 3. Number of PLHIV known to be on ART 12 months after initiating it 4. Stock outs occurred (ARVs) – name of ARV, number of days of stock-out, reason (if known) 5. Stock outs occurred (HIV test) – type of test (rapid, blood), number of days of stock-out, reason (if known) 6. Stock-outs occurred (HIV test lab supplies) – type of supplies (consumables and/or durables), number of days of stock-out, reason (if known)	7. Stock-outs or issue occurred (HIV testing equipment) – type of equipment, number of days of stock-out, reason (if known) 8. Stock-outs occurred (viral load test lab supplies) – type of supplies, number of days of stock-out, reason (if known) 9. Stock-outs or issue occurred (viral load test lab equipment) – type of equipment, number of days of stock-out or broken, reason (if known)
VIRAL SUPPRESSION	1. Number of PLHIV that have received a viral load test 2. Number of PLHIV that received their viral load test results within two weeks of taking the test	3. Number of PLHIV on ART who have achieved viral suppression

TABLE 2 Examples of qualitative indicators that can be collected by CTOs

AREA OF FOCUS	INDICATOR	
PREVENTION AND TESTING	1. What are the reasons for people not receiving an HIV test? 2. What are the reasons for people not receiving their HIV test results?	3. What are the local and/or national eligibility criteria for gaining access to pre-exposure prophylaxis (PrEP)? 4. What are the local and/or national eligibility criteria for gaining access to post-exposure prophylaxis (PEP)
CARE & TREATMENT	1. What are the reasons why PLHIV are not accessing ART? 2. What are the reasons for stock-out? 3. How would you rate the overall quality of service at your health facility? (Scale: 1 to 5; 5 being highest)	4. Were you treated with respect by your health care worker today? 5. Any other issues that arise in discussion related to care and treatment
VIRAL SUPPRESSION	1. What are the reasons for PLHIV not receiving a viral load test?	2. Any other issues that arise in discussion related to care and treatment

WHAT IS THE ADDED VALUE OF COMMUNITY TREATMENT OBSERVATORIES?

Community treatment observatories serve as a watch-dog mechanism for health and social service delivery systems. When communities are neglected, marginalized, or disconnected from decision-making processes, CTOs provide them with a way to ensure that health systems respond to their needs—and recognize their rights.

CTOs provide a comprehensive picture of both the quantity and quality of services that a setting provides. In this way, they can track uptake of services, while monitoring quality of care. Even in settings where community data is being adequately captured through existing monitoring systems, such as national registries, it is not always available to recipients of care or civil society. Thus, CTOs play a valuable role in enabling community to see health systems data -- even if it is the same as what is being collected through national health management information system (HMIS).

CTOs play a key role in monitoring HIV services and informing targeted advocacy actions that can improve access to, and quality of those services, particularly for underserved and key populations (e.g. migrants, adolescents, men who have sex with men (MSM), sex workers, people who inject drugs (PWID), prisoners, and transgender people).

CTOs help to streamline and standardize all treatment access data, and ensure that the questions and issues important to people living with, and affected by HIV are integrated into the process. Monitoring treatment programs at country-level often focuses primarily on quantitative indicators, with little information available on the qualitative aspects of service delivery. When such data exist, it is often collected in a fragmented way - and not always effective for advocacy purposes. The systematic and continuous monitoring process of CTOs can help overcome these issues. In these ways, CTOs provide valuable information that can be used to hold health care providers, funders and governments accountable, and to create positive dialogue around these issues.

CTO data can help to:

■ Supplement HMIS data, by collecting data that is difficult for them to collect or would otherwise be excluded.

■ Produce shadow reports that hold governments accountable and highlight issues that are not included in government reports.

■ Provide better insights on issues around access and quality along the HIV cascade, which can be used to identify, prioritize and respond to treatment and service gaps.

■ Provide insights for community members to develop and assess demand creation strategies, which often play a critical role linking people to services.

■ Build evidence to inform civil society and community advocacy for improved care and services.

CTOs also play a critical role in community systems strengthening (CSS), by involving community members in the design, delivery, monitoring, and evaluation of services aimed at improving their health. Successfully implemented CTOs also empower PLHIV to advocate for access to optimal HIV services by:

■ Increasing knowledge and capacity among PLHIV and key populations so that they are aware of the quality standards for HIV treatment, and how to monitor service delivery.

■ Building a community-driven evidence base on the need for, availability and continuity of, and access to quality of HIV services.

■ Building capacity among implementing partners (e.g. PLHIV networks) in terms of organizational strength, governance, and technical competence (i.e. in monitoring & evaluation [M&E], program design, and implementation).

HOW DO COMMUNITY TREATMENT OBSERVATORIES WORK?

In a CTO, an organized group of community members—such as networks of PLHIV—are trained to collect data on various aspects of HIV prevention, care, and treatment. This data is collected at set intervals (usually monthly or quarterly) and entered into a centralized database. After data from all sites has been collated and checked for quality, it is analyzed. As data is being systematically and routinely collected, PLHIV networks and community members can use it to conduct comparative analyses that monitor trends over time, and to inform targeted advocacy efforts.

Guiding Principles of a CTO

Community treatment observatories are developed and conducted in accordance with four key components: Education, Evidence, Advocacy, and Engagement.

■ **Education**. Through interactive treatment education trainings, community members gain a working knowledge of HIV pathogenesis and transmission; the prevention, testing, care and treatment cascade, including optimized ART; service delivery; viral load monitoring, and human rights issues. This critical component ensures that community members understand the implications of their national treatment guidelines in the context of current targets, declarations, and internationally recognized standards for HIV treatment and services (e.g. Fast-Track, UNAIDS 90-90-90 Targets, Sustainable Development Goals, WHO guidelines), and it is the foundation for reviewing, monitoring and evaluating the implementation of these guidelines.

■ **Evidence**. Community members collect and generate data to identify barriers to HIV treatment access. This is often the most visible component of a CTO's work, because it incorporates the majority of the mechanism's structure, process and operational flow. It involves situational analysis and mapping processes, data collection, data verification, data entry and cleaning, data analysis—including monitoring for trends—and data quality audits. Each of these steps is explained in more detail in the Setting Up a CTO section on page 10.

■ **Advocacy**. In order for CTOs to have maximum impact, community members must use the skills and knowledge gained through Education to develop and conduct actionable activities, which are based on the data and information generated by Evidence gathering. The resulting evidence-based advocacy promotes equitable access to prevention, care, and treatment services. Advocacy is also vital to ensuring treatment affordability and sustainability for all people living with HIV, and to identify stigma, discrimination, and structural barriers.

- **Engagement**. CTOs operate within a larger system of stakeholders who can influence access to, and quality of health services. This includes Ministries of Health, National AIDS Councils, health care providers, technical partners, multi- and bi-lateral organizations, and donors. As such, it is important for CTOs to build momentum through strategic partnerships. This includes engaging policy makers and Country Coordinating Mechanisms (CCMs); soliciting partnerships with stakeholders that have common interests; conducting community sensitization and establishing CCGs.

Structure of a CTO

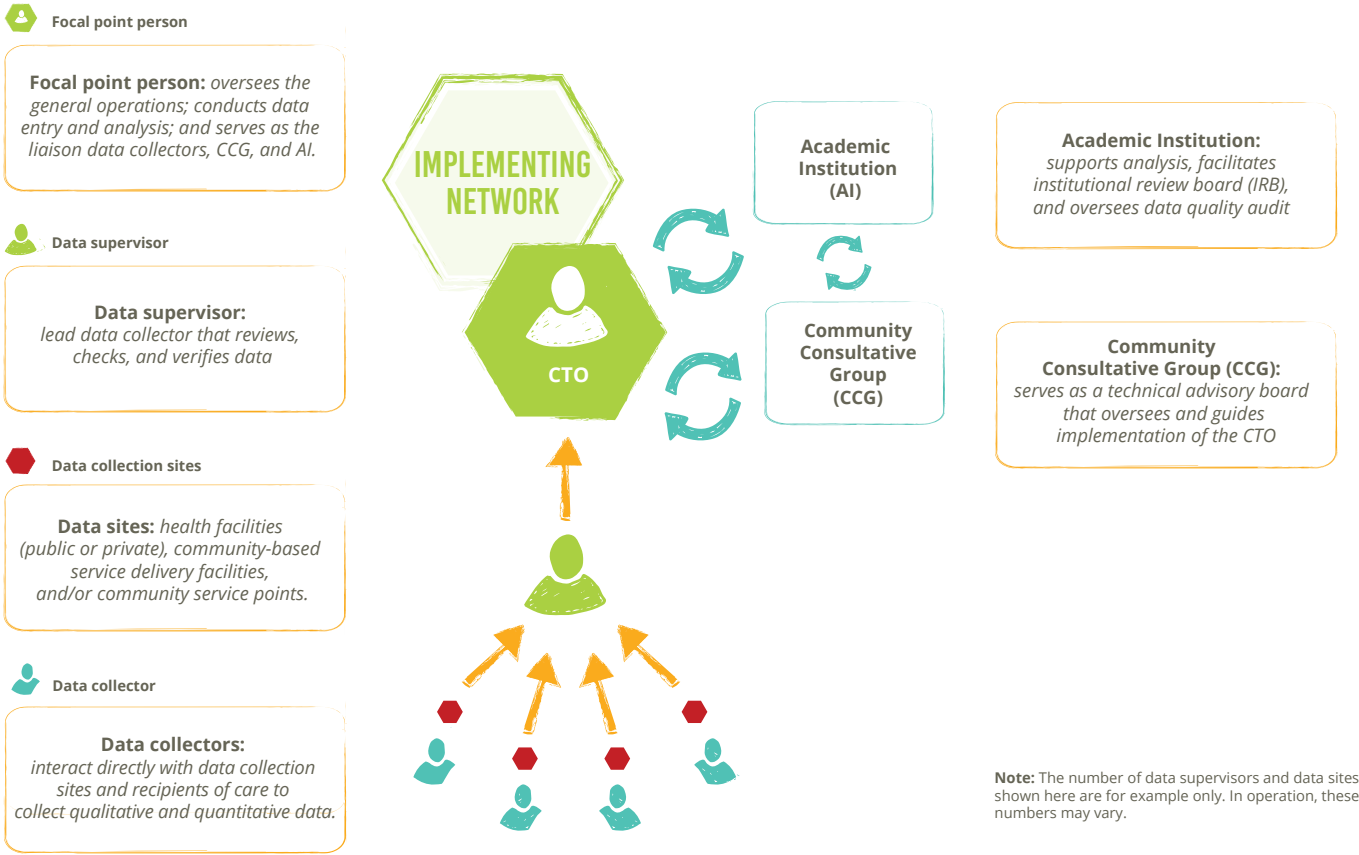The basic structure of a community treatment observatory includes five basic components:

1. **Implementing Network**. To create a solid foundation for a CTO's sustainability, it should be embedded in, and owned by an existing institution or organization—such as a national network of people living with HIV. This ensures that the observatory is integrated within the larger system, and community-owned to last. It should not be built as a stand-alone project. See more about sustainability on page 16.

2. **Focal point person**. The focal point person is a full-time position that oversees the general operation of the CTO and serves as the liaison between data collectors, the CCG, academic institutions and any external stakeholders. After data has been collected, verified, and collated, it is submitted to a focal point, who is responsible for entering the data into the centralized database. In large-scale operations, the responsibilities of the focal point can be delegated among several positions (e.g. operational oversight, staff supervision, and data entry can be assigned to three people).

3. **Data collection sites**. Data collection sites are health facilities (public or private), community-based service delivery facilities, and/or community service points (e.g. community ARV groups) where data will be collected.

4. **Data collectors**. Data collectors are responsible for data collection from a specific number of sites. Data collectors interact directly with these sites (i.e. health facilities or service delivery points) to collect quantitative data. They also collect qualitative data by conducting key informant interviews and holding focus group discussions with recipients of care, community members, and other stakeholders. One data collector per site is usually sufficient, but this varies, depending on the volume and frequency of data collection. For example, in cases where data collectors only need to visit data sites once per month for quantitative data, it could be feasible (and more efficient) to have one data collector cover multiple sites.

5. **Data supervisor**. A lead data collector is responsible for collating data across all data collection sites and conducting data verification and cleaning the data. Depending on the number of data collection sites, there may be several data supervisors who each manage a team of data collectors and the data collection from corresponding sites.

6. **Community consultative group (CCG)**. In order to ensure that the CTO is responsive to community needs, the implementing network must work collaboratively with a CCG. The CCG provides input into the development of data collection tools, supports the implementation of the CTO, provides support on data analysis, and gives direction on organizational decisions. The CCG is comprised of key stakeholders (e.g. government, partners, experts in the field) and includes representatives from community and key population groups (e.g. youth, women living with HIV, MSM, PWID, sex workers and others), based on community needs and priorities.

7. **Academic institution**. A partnership with an academic institution is invaluable for helping to build capacity among community members within the CTO. Ideally, a locally-based academic partner will provide on-going technical assistance, support for developing the data collection tool and performing data analysis, and data quality audits. Academic institutions can also help to facilitate ethical processes and an institutional review board (IRB). Academic partners can also help to publish and disseminate the CTO's data in peer-reviewed journals and at conferences. If a formal relationship with an academic institution is not possible, other external partners or individuals—such as graduate students, research experts, consultants, or technical agencies—can provide support for these processes.

CTOs have the same structure, regardless of what level they work at. For CTOs operating at regional-level (i.e. across multiple countries), the structure can be scaled so that all of the national-level CTOs feed into a single regional CTO, which will then aggregate the data and information at a regional level. An example of how this is being done is provided in the Case Studies section, which details the Regional Community Treatment Observatory in West Africa on page 18. Similarly, CTOs can operate

FIGURE 3
ITPC's CTO Structure.
The basic structure of a community treatment observatory includes five basic components

Focal point person

Focal point person: *oversees the general operations; conducts data entry and analysis; and serves as the liaison data collectors, CCG, and AI.*

Data supervisor

Data supervisor: *lead data collector that reviews, checks, and verifies data*

Data collection sites

Data sites: *health facilities (public or private), community-based service delivery facilities, and/or community service points.*

Data collector

Data collectors: *interact directly with data collection sites and recipients of care to collect qualitative and quantitative data.*

IMPLEMENTING NETWORK

CTO

Academic Institution (AI)

Academic Institution: *supports analysis, facilitates institutional review board (IRB), and oversees data quality audit*

Community Consultative Group (CCG)

Community Consultative Group (CCG): *serves as a technical advisory board that oversees and guides implementation of the CTO*

Note: The number of data supervisors and data sites shown here are for example only. In operation, these numbers may vary.

at global-level, by having national-level CTOs feed into regional CTOs, which then feed into a global CTO that will aggregate and analyze the data.

Setting Up a CTO

Developing and implementing a functional CTO involves several important steps and processes, as follows:

1. Pre-Implementation Preparations. setting up a CTO requires extensive pre-implementation planning. This includes:

- **Development of an Operational Plan and Performance Framework**. An operational plan and performance framework describe the scope of what the CTO will monitor, explain how to initiate this work, and evaluate the CTO's performance. These critical management documents will guide and frame the scope, implementation, and efficiency of the observatory. They should include measures to track work plans and set operational performance standards. Where possible, in-depth organizational capacity assessments should be conducted by an external third party, to evaluate governance systems and policies.

- **Development of Data Collection Tools and Database Platform**. Once there is an operational plan to outline the scope of what the CTO will monitor, the next step is to develop both a monitoring plan and a data collection tool. The data collection tool includes indicators for monitoring service delivery and treatment access issues. The monitoring plan outlines key protocols for how data collection will happen, from initial data collection to analysis. This includes specifying the frequency of data collection, identifying the sources that are required for data verification and outlining a clear method for reviewing data quality. After the data collection tool is developed, a database

Protecting Communities, First & Foremost

As with all community-led research, CTOs must ensure the confidentiality, safety and security of people who access care at the health facilities that are being monitored— especially in places where PLHIV and members of key populations are stigmatized and criminalized. CTO implementers and all staff must impose ethical standards and ensure that all personnel receive proper training on how to handle, store, analyze, and disseminate data. Implementers should also agree with all data sites (i.e. health facility partners) on a standard protocol for handling patient and/or health data files and outline this as part of the MOU or working agreement.

platform is designed (or adapted from an existing platform) to host the data that will be collected. The database must be secure and accessible only to authorized implementers (as directed by and allowed under the ethics approval). The database should be designed to allow users to draw comparisons between treatment centers or countries, and create interactive graphs, tables and maps.

CRITICAL CONCEPTS THAT INCREASE THE CREDIBILITY OF CTO DATA

Having robust CTO data, and by extension the related evidence-informed advocacy, depends almost entirely on appropriate data plan design and methodology for data collection. Given that these decisions can become quite complex, partnering with an academic institution is vital for CTO functionality (See page 9 for more on partners). Below, details on sample size and selection are outlined.

Sample Size and Confidence Intervals: CTO data collection sites should be randomly selected to ensure a representative sample of the population. The larger the sample size, the more likely that your data will reflect the average among a population. For example, your estimate of the average height among men in a city will be more accurate if your sample is larger. If your sample is too small, a very tall or very short person could throw off the average. CTOs should calculate their sample size based on a 95% confidence interval. The wider the confidence interval is, the more likely it is that it will reflect the true average. Where resources allow, ITPC recommends a 99% confidence interval to decrease the probability of random error. To determine the right sample size

for ensuring accuracy, a sample size reference table is available in the Annexes. Online sample size calculators are also readily available. As an example: In order to get a representative sample of the 6.1 million PLHIV in West and Central Africa, one should aim to survey around 16,600 PLHIV.

Sampling and Selection: In addition to a sufficient sample size, it is also critical that the sample is randomly selected. There are a number of approaches to sampling that should be considered depending on the outcomes of interest. For example, you may want to do simple random sampling, where each site has an equal probability of being included; or do a weighted random sampling where each client is the sampling unit. Other considerations can include:

- Volume of clients at a site (high volume vs. low volume)
- Feasibility of implementation
- Need for particular disaggregation by:
  - Rural vs. urban
  - Key populations
  - Age

- **Establishment of CCG and Academic Institution Partnership** –The CCG and academic partners provide operational oversight and important technical assistance. Partnership with an academic institution should be formalized through a memorandum of understanding (MOU) or contract.

- **Selection and Engagement of Data Collection Sites**. The data collection sites are identified based on the selection criteria outlined in the monitoring plan. The selection criteria include factors such as urban vs. rural, HIV prevalence, recipient of care volume, large hospital vs.

community centers, and willingness to participate. Once sites are selected, a formalized partnership should be established between the CTO and the site, via an MOU or other working agreement. Depending on the type of data site (e.g. public health facility), it may also be necessary to establish a working agreement with the Ministry of Health, to ensure that the CTO will be able to access and collect data as needed.

Selection of data sites and recruitment of the CTO implementing team can happen in parallel. Although the two processes are distinct, they can inform each other. For

example, if the CTO is only able to recruit data collectors within a certain province due to budgetary constraints, this will inform the selection of data sites—limiting them only to sites within that province. Likewise, if the CTO has selected data sites in a province that speaks a certain dialect, this will limit the selection of data collectors to those who speak that dialect.

- **Ethical Approval**. Institutional Review Boards (IRBs) and Independent Ethics Committees (IECs) are administrative bodies established to protect the rights and welfare of people who participate in research. CTOs must obtain ethical approval to ensure that they have the necessary systems in place to protect the rights of people and communities that it is

meant to serve. This process can be difficult, and it may take a significant amount of time to complete (given the unique requirements of each country, and the frequency of IRB and IEC meetings), so it is ideal to review submission requirements early, and submit documents as early as possible (i.e. several months in advance). The academic institution and other experts from the CTO's CCG can help facilitate this process.

- **Training of CTO Implementing Team**. The focal point lead and the data collection team are trained: 1.) to fully understand the package of care and treatment (based on the latest WHO guidelines), and 2.) to properly use the data collection tool. This includes training

on HIV pathogenesis and transmission, as well as WHO-recommended prevention, testing and treatment and service delivery, and a hands-on workshop covering the content of the indicators and use of data collection tools (including any applicable hardware and software). ITPC's CTO trainings are usually three to five days long. The data supervisor(s) and the focal point lead undergo additional training specific to their particular roles.

- **Conduct of Baseline Assessment**. The CTO should conduct a baseline assessment to document the initial status of all quantitative and qualitative indicators. Over time, data can be compared to the baseline assessment to monitor trends and track improvements (or declines) in treatment access and service quality.

2. **Operationalization**. Once pre-implementation preparations are complete and the foundational structures of the CTO are in place, monitoring can begin.

- **Data Collection**. Data collectors begin their work, using finalized data collection tool(s) at each site, at the frequency specified in the final operational plan (e.g. monthly or quarterly).

- **Data Verification**. The data supervisor(s) review submitted data, verify information sources, and validate the data at monthly or quarterly intervals, as specified in the final operational plan.

- **Data Entry**. Once the data has been verified, data supervisors deliver it to the focal point lead or other designated team member, who enters it into the database. During this time, the focal point lead consults regularly with the CCG and academic institution to highlight any best practices/challenges in the data collection process and system, and to problem-solve and provide follow up.

- **Data Management and Storage**. If data is being collected with a standard paper-based form and/or questionnaire, the operational plan should outline standard procedures for safeguarding, storing, and/or discarding the paper forms after they are entered into the computer database. The procedure for storing or discarding paper forms should comply with required IRB protocols, to ensure safeguarding of sensitive or identifying information. Physical forms, questionnaires, notes from meetings, and any other reports from interviews and focus group discussions should be stored in lockable cabinets. Documents may also be scanned and uploaded to a central database as backup, to minimize loss of data and for data security. If data is being collected electronically, management procedures should ensure data is recorded and stored in standardized formats, to ensure consistency so that it is easy to access, review, analyze and report.

- **Data Review and Analysis**. After data is entered into the database, the CTO's focal point lead performs a first-level analysis to verify its timeliness, completion, clarity, and coherence. If there are no issues that require additional review, the focal point (and/or monitoring and evaluation specialist, if part of the implementing team) can begin conducting a more in-depth analysis. Key considerations for analysis include:

  Is the data demonstrating progress towards targets?

  Is it possible to link data to any outcomes?

  Which data is most useful for advocacy?

  Are there any indicators for which data has not been available? If so, why? Is the indicator still relevant?

  Are there any data or trends in the data that raise questions? If so, what are the next steps for addressing these?

FIGURE 4
ITPC's CTO Operational Data Flow
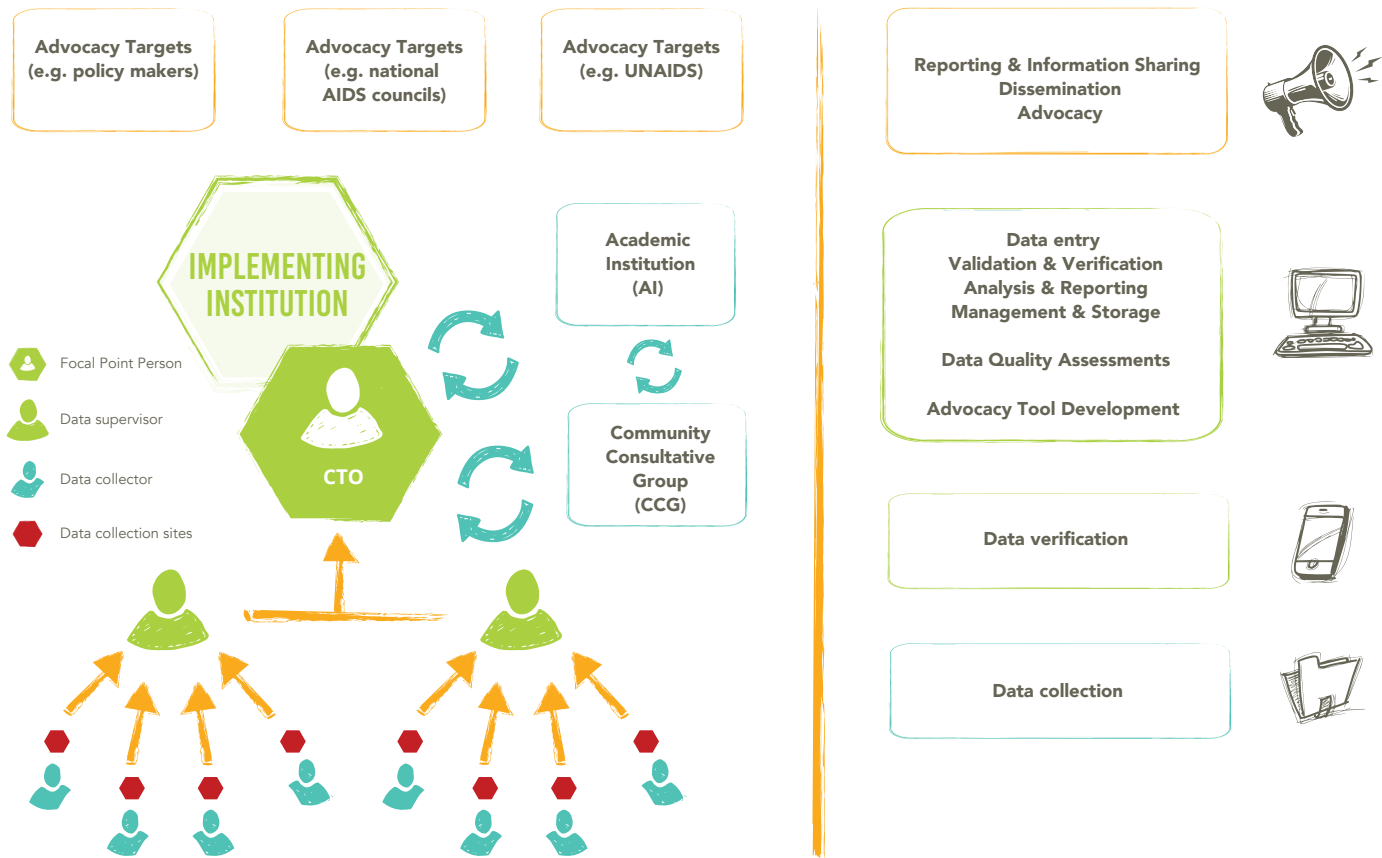
- **Data Quality Audit**. In addition to routine data quality review and analysis by data supervisor(s) and the focal point, it is critical to conduct formal data supervision and quality assessments (DSQAs). This involves field visits where the implementing team can troubleshoot any issues that would lead to inaccurate, incomplete and unreliable data.

3. **Using the Data**. Once data has been analyzed and audited, it is ready to be shared, disseminated, and used to inform advocacy actions.

- **Information Sharing**. Since the CTO's data collection is ongoing, creating a communications or information dissemination plan may be beneficial. Information sharing includes the development of communications products (e.g. research briefs, presentations) and platforms for disseminating key findings. For regional- or global-level CTOs, it may be useful to have cross-cutting platforms such as websites and listservs, where national-level updates can be consolidated—as is currently being done through ITPC's *Watch What Matters* website. Relationships should also be built with key stakeholders and media, and key findings and data can be shared with them regularly.

  - **Feedback**. Over and beyond information sharing, a critical component of using the data is gaining insights from communities and health facilities where it is collected. This ensures that communities and health facilities can respond to and give feedback on analyzed data and any noticeable trends and bring actionable solutions to the table. Solutions can be implemented in real-time, or over the long-term. This step is often missing from other models of health systems monitoring. Although data may be used to demand action from national- and/or regional-level

stakeholders this more immediate and direct feedback loop allows PLHIV activists and health systems to implement simple, immediate and effective community-level changes.

- **Advocacy**. Community members can use the data and subsequent analysis to inform the development of advocacy strategies and campaigns; in reports that are shared via communication platforms, and with key stakeholders, such as PLHIV networks and advocates, health facilities (including those where data is being collected), care providers, policy makers, national AIDS programs, and funders. As with any advocacy report, it is important to identify and include key recommendations for improving quality and coverage of services.

Standards & Accreditation of a CTO

As the CTO becomes operational, the implementing team should review the operational plan and performance framework, to ensure that it is operating according to these standards. This is an ongoing, annual process that involves both the network of community members and the CCG.

ITPC has developed a minimum set of standards to ensure that CTOs are functional, responsive, and beneficial to the communities they seek to support. The accreditation standards cover aspects of governance, partnership management, organizational management, data management, and technical capacity. CTOs meeting these minimum standards can receive accreditation as an ITPC CTO, after undergoing an independent review that evaluates their performance against these standards. Table 3 lists examples of accreditation standards and the evaluation criteria used as part of ITPC's CTO accreditation process.

TABLE 3 Examples of CTO Accreditation Standards

STANDARD	EVALUATION CRITERIA
GOVERNANCE & ACCOUNTABILITY *The implementing network demonstrates good governance and accountability practices*	• **Good:** The organization has good governance structures and systems in place to uphold accountability. Existence of a board that meets regularly, (i.e. at least four times a year), including at annual general meetings; existence of a board constitution; minutes from board and staff meetings; documentation that the CTO is in compliance with national laws and regulations; evidence of clear and transparent decision-making processes and strong capacity and systems for effective management and oversight. • **Fair:** The organization has some governance structures and systems in place to uphold accountability. Existence of a board, although it does not meet regularly (i.e. less than four times a year). The organization has some capacity and systems for effective management and oversight. • **Poor:** The organization has no governance structures (e.g. no board). It is not registered in the country that it is operating in and has no fiscal sponsors or systems in place to uphold accountability. The organization does not have the capacity and systems for effective management and oversight.
PERSONNEL *The implementing network has adequate and skilled staff (program, finance, M&E, etc.)*	• **Good:** The organization has an adequate number of skilled staff members to perform its duties (program, finance, M&E, etc.). Staff performance is continuously assessed and refresher trainings are provided for building their capacity. • **Fair:** The organization has a somewhat adequate number of skilled staff members to perform its duties. Draft terms of reference or job descriptions or a human resources manual are available. • **Poor:** The organization does not have adequate or skilled staff members to perform its duties. Staff roles and responsibilities are not defined. Terms of reference or job descriptions or human resources manual are not available.
DATA COLLECTION *The CTO has an established mechanism to systematically and accurately collect data at designated sites and a system for oversight of data collectors*	• **Good:** Solid systems are in place to collect and store the data (i.e. data collection tools, database, secured storage for the completed data forms, consent forms, IRB paperwork, etc.). Data collection processes are audited and well managed by the CTO focal point and/or M&E staff. • **Fair:** Limited systems are in place to collect and store the data; however, the systems and tools are not consistently used or implemented effectively. • **Poor:** No systems are in place to collect and store the data.
NATIONAL INTEGRATION *The CTO is integrated in the national context and involved in the Community Consultative Group (CCG) and the Country Coordination Mechanism (CCM)*	• **Good:** Regular interactions between the CTO and the CCG or CCM. National interest in providing resources for and sustaining the CTO. CTO data integrated into HIMS or used to inform national strategic plans. • **Fair:** Some interactions between the CTO and the CCG or CCM. • **Poor:** The CTO has no interactions with the national CCG or CCM.

KEY CONSIDERATIONS IN SETTING UP A COMMUNITY TREATMENT OBSERVATORY

Application and Adaptability

ITPC's CTO Model can be applied at scale in various communities, across countries and regions, and in the context of nearly any health or social justice issue. In the context of HIV, it has been adapted to monitor specific aspects of HIV care—for example, HIV prevention among PWID–and to more broadly monitor a variety of issues within West Africa. So long as the metrics and indicators are informed by, and meaningful to communities, CTOs can help uncover access barriers and opportunities to advocate for change.

The structure of a CTO is the same regardless of whether the CTO is operating at the facility level or at the national level. An example of how this is being done in West Africa's Regional Community Treatment Observatory is provided in the Case Studies section on page 18.

Funding and Sustainability

- **Technical capacity and sustainability**. Investment in the knowledge, skills, and technical capacity of community members and their networks is critical to the success of a CTO. Data collection tools cannot be developed and used in isolation; the implementing team's technical skills and capacity must be maintained and expanded. This means ensuring that people (e.g. data collectors, focal point leads, etc.) are properly trained and given the necessary tools and resources for performing their respective roles. In many cases, training must be an on-going process that addresses emerging challenges and provides updated information.

- **Systems sustainability**. It is critical that a CTO is embedded in and owned by an existing structure or organization—such as a national network of people living with HIV. It should not be built as a stand-alone project. The structure or national network must have the capacity to house such an operation, including the necessary systems for governance, monitoring and evaluation, financial management, and communications. This ensures that the CTO is integrated into a larger system, community-owned and sustainable. **CTOs play a critical role in community systems strengthening (CSS), by developing the roles for community members to design, deliver, monitor, and evaluate services aimed at improving health.**

- **Financial sustainability**. The financial cost of implementing a CTO is an important consideration. Operational costs should include salaries, stipends, transportation, database and technology investments, and overhead (office rent, electricity, phone, utilities, and support for implementation of advocacy issues, etc.). **It is important to cost the needs of a CTO accurately and realistically before implementation, to ensure that sufficient funding is secured. Based on ITPC's experience, implementing and operating CTO can range between US$ 100,000—150,000 annually.** This includes costs for data collection, data management and analysis, project operations and personnel, trainings/capacity building, advocacy interventions, hosting stakeholder meetings (i.e. CCGs), and monitoring visits/data quality audits. This cost range varies by country, based on general cost of living, number of data collection sites, use of paper-based versus digital data collection, number of personnel, distance between data collection sites, and location of data collection sites (urban/peri-urban/rural). This is why core funding to build and maintain these basic and essential capacities is critical—and needs to be prioritized.

Risk Mitigation

Risk mitigation strategies are an important part of ensuring CTO sustainability. They must consider factors including complex and sometimes unstable national contexts, differentiated interventions that are based on community needs, cost-effective activities that maximize the impacts from a limited budget, coordination with existing initiatives to ensure synergy among national and regional projects, and the absorptive capacity of organized community networks.

Organizations and institutions–interested in creating a CTO should also examine national-, regional- and global-level political and environmental contexts to determine if and how they will impact their work, and develop appropriate precautions as needed.

Other Models of Community Monitoring

Community observatories are currently being implemented all over the world in various contexts. This model is the standard by which ITPC's CTOs operate within our larger community monitoring initiative—called *Watch What Matters*—which includes other models of community-based monitoring.

Other models of community-based monitoring—such as ITPC's *Missing the Target* report series—also provide means by which communities can develop the evidence-base they need to inform their advocacy.

GETTING MONEY FOR A CTO

In the ever-shrinking HIV funding landscape, it can be difficult to find donors to support community-led monitoring. However, **core funding is essential for building, maintaining and updating a CTO's basic functions. Although the amount may be minimal, core funding needs to be prioritized in costing models to ensure the sustainability of the CTO.**

Implementing networks interested in building a CTO should be aware of:

- The national context - including the HIV epidemic in their country.

- Any other monitoring initiatives, including other CTO working in the country and/or region.

- Opportunities for key and strategic partnerships, for example with interested academic partners, etc.

In addition, it is important to:

- Conduct donor mapping (to determine who funds what in your region)

- Develop an elevator pitch that synthesizes in a few sentences what you are trying to do and why

If no funding is available, try to keep doing what you're doing the best you can - it matters!

CASE STUDIES

CASE STUDY #1:

The Regional Community Treatment Observatory in West Africa (RCTO-WA)

In February 2017, ITPC, with support from the Global Fund, launched the Regional Community Treatment Observatory in West Africa (RCTO-WA). Building on previous work that monitors ARV stock-outs in the region, the RCTO-WA aims to increase HIV treatment access in 11 West African countries: Benin, Cote d'Ivoire, The Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Senegal, Sierra Leone, and Togo; by (1) formalizing and expanding existing community treatment observatories to all focus countries; (2) creating a regional treatment observatory; and (3) by building capacity among members of the 11 national PLHIV networks to do treatment monitoring. Housed under our Watch What Matters campaign, the project follows ITPC's Community Monitoring Model (Figure 1). The three-year project focuses specifically on five

key and vulnerable populations—MSM, sex workers, 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.

There was an extensive pre-implementation process before the RCTO-WA was launched in February of 2017. It included 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, national PLHIV networks were identified as in-country partners to lead implementation of the national CTOs. A series of three technical planning workshops were held between

FIGURE 5

Total Number of PLHIV Who Received a Viral Load Test Versus the Number of PLHIV Who Received Their Viral Load Test Result Within Two Weeks– (cumulative January - June 2018)
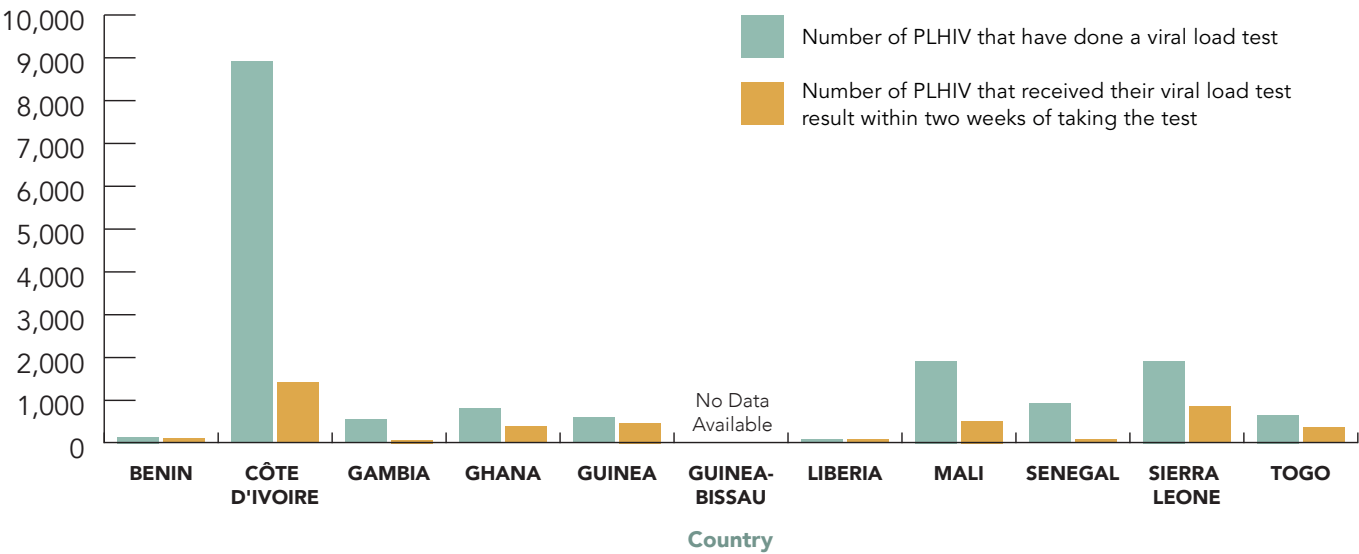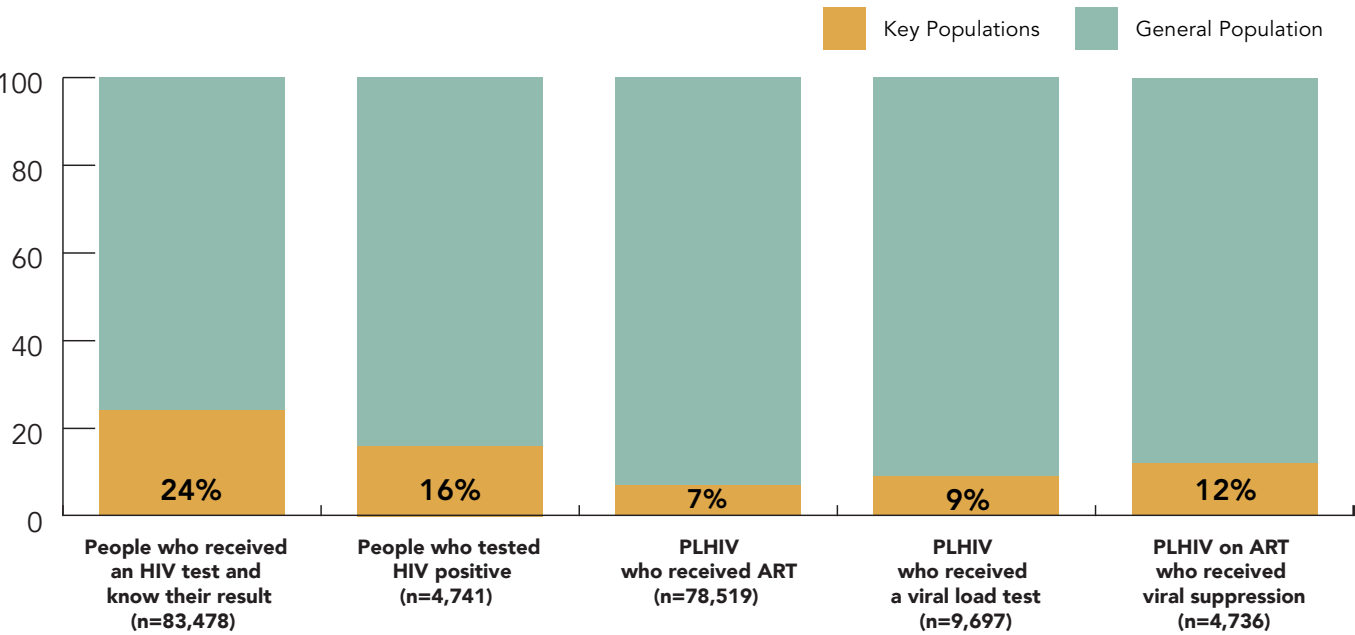

FIGURE 6

Key Populations Reached Along the Cascade, as a Proportion of All People Reached at CTO-Monitored Health Facilities

December 2016 and February 2017 to train implementation teams from each country. These workshops focused specifically on work planning and capacity building for 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)—and trained local data collectors. Data sites in each country were selected based on specific criteria (i.e. population size, geographic coverage, accessibility), and signed MOUs to become designated data collection sites.

Data is collected from these sites using standardized paper-based data collection tools (developed in English, French, and Portuguese), which is then manually entered into an electronic web-based database and archiving system, which allows for collection of scanned documents to facilitate data flow and data quality assessments. The RCTO-WA database includes an online dashboard (also developed in English, French, and Portuguese) where all partners enter quantitative and qualitative data. Both the quantitative and

qualitative indicator sets monitor issues along the entire HIV cascade, specifically prevention, testing, ART initiation, and treatment monitoring (Table 1).

To date, the data and initial findings of the RCTO-WA paint a clear and specific picture of the experiences among communities in West Africa, where sigma and discrimination, lack of knowledge and awareness about HIV, procurement failures and user fees prevent key populations from accessing the prevention and treatment services they want and need. For example, there is a stark disparity between the total number of PLHIV that have done a viral load test and the number of those received their test result within two weeks (Figure 5).

It is clear that that the absorptive potential and the critical need for viral load testing are not being met—and even where it is, results often fail to reach recipients of care—rendering the test meaningless in the lives of people living with HIV.

When national data only report the number of viral load tests completed, the full picture remains unseen. As the RCTO-WA data show,

viral load testing is not being done routinely (as recommended by WHO), and test results are not reaching recipients of care; therefore, this essential information is not being used to help PLHIV achieve viral suppression via adherence counseling and/or switching to a new regimen. Qualitative data reveal that average turnaround time for viral load test results is 4.5 months from the time of test.

What is most notable is the data, or lack thereof, on access to services by specific populations. Data from some groups—e.g. pregnant women—are better captured by the health system, while others remain unseen. RCTO-WA data show disproportionate gaps in the HIV care cascade for key populations (Figure 6). These data highlight significant access barriers for these groups, especially around linkage to care and ART initiation. In addition, just 38 out of 101 RCTO-monitored health facilities report data for at least one key population, creating additional challenges for holding health service providers accountable..

CASE STUDY #2:
CTOs in East, West, and Central Africa, Latin America and the Caribbean

In 2015, with the support of Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ), CTOs were formalized in East Africa, West Africa, Central Africa, Latin America and the Caribbean. Each CTO was designed to catalyze activism, strengthen capacity among national treatment advocates, and enable networks of PLHIV and key populations to monitor the effectiveness of financial investments in health. In most cases, CTOs focused on monitoring the management of Global Fund resources, as a watch-dog mechanism to avert mismanagement of funds.

In East Africa, ITPC focused on monitoring country coordinating mechanism (CCM) management and transparency issues around

the use of Global Fund resources in Kenya, Uganda, and Tanzania.

In West Africa, ITPC collected data on state of treatment, with emphasis on stock-outs in Côte d'Ivoire, The Gambia, and Sierra Leone. More than 150 community treatment advocates were trained. Key findings from the observatory have been used for regional, national and local advocacy. The observatory in West Africa established an initial foundation for what became the Regional Community Treatment Observatory in West Africa (RCTO-WA) in 2017.

In Central Africa, ITPC monitored the meaningful engagement of key populations in the CCMs in Central African Republic, Democratic Republic of Congo, and Cameroon. As a result of this process, the priorities of key populations were integrated into Global Fund concept notes that were submitted by regional platforms.

In Latin America and the Caribbean, ITPC monitored supply chain management issues, with a particular focus on stock-outs and management of Global Fund resources. The observatory trained 50 community leaders and established two treatment committees. Early stock-out warnings from the committees prevented stock-outs from occurring in the areas that were monitored by the observatory.

ANNEX

ANNEX 1 Sample Size Table

POPULATION SIZE (i.e. total number of people living with HIV in the country or region)	MINIMUM RECOMMENDED CTO SAMPLE SIZE (i.e. number of people living with HIV receiving care at CTO sites)
1000-1,999	700
2000-2,999	780
3,000-3,999	850
4,000-4,999	880
5,000-9,999	965
10,000-19,999	2200
20,000-29,999	7300
30,000-39,999	7700
40,000-49,999	8000
50,000-99,999	8700
100,000-149,999	9000
150,000-199,999	9100
200,000-249,999	9200
250,000-299,999	9300
300,000-499,999	9400
500,000-999,999	9500
1,000,000+	9600

ENDNOTES

1 UNAIDS. *Miles to go – closing gaps, breaking barriers, righting injustices.* Global AIDS Update. 2018.

2 Kentoffio, K., Kraemer, J. D., Griffiths, T., Kenny, A., Panjabi, R., Sechler, G. A., ... & Siedner, M. J. (2016). Charting health system reconstruction in post-war Liberia: a comparison of rural vs. remote healthcare utilization. BMC health services research, 16(1), 478.

3 By 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.

4 Kruk, Margaret E., Anna D. Gage, Naima T. Joseph, Goodarz Danaei, Sebastián García-Saisó, and Joshua A. Salomon. "Mortality due to low-quality health systems in the universal health coverage era: a systematic analysis of amenable deaths in 137 countries." The Lancet (2018).

5 WHO. Consolidated Guidelines on Person-Centered HIV Patient Monitoring and Case Surveillance [Online]. June 2017.

6 FHI 360/LINKAGES. *HIV Cascade Framework for Key Populations.* Oct 2015.

7 The Global Fund to Fight AIDS, Tuberculosis, and Malaria. Community Systems Strengthening Framework. 2014.

8 For a 95% confidence interval and a 1% margin of error. To ensure smaller CTOs are still practical to set up, in populations 10,000-20,000, a 2% margin of error is used. For populations smaller than 10,000, a 3% margin of error is used.

Watch What Matters is a community monitoring and research initiative to gather data on access and quality of HIV treatment globally.

Visit WatchWhatMatters.org for the latest news and updates from the Regional Community Treatment Observatory in West Africa and other community-based monitoring projects.