WHAT IS A CTO AND HOW DOES IT WORK?

Community-led monitoring offers the potential to increase oversight of, and advocacy for improvements to HIV services.

A CTO is a mechanism that systematically and routinely collects and analyzes qualitative and quantitative data. Using metrics and indicators informed by, and meaningful to communities of people living with HIV, this data is used to identify gaps in essential services, and to inform advocacy for improving them.

In a CTO, community members—such as networks of people living with HIV, collect data on various aspects of prevention, testing, care, and treatment services. They work with a community consultative group (CCG) and academic partners to identify key HIV services and collect data on access to, and quality of these services at national, regional and global levels. Figure 1 shows how community monitoring can assess service provision along the entire HIV care cascade.

Unlike other community monitoring or research mechanisms, CTOs are a systematic and continuous. Figure 2 shows the basic structure and operational flow of a CTO.

At regular intervals (e.g. monthly), data collectors gather information at sites where HIV services are delivered. When data is collected, supervisors review it, verify its sources, and validate it. When this process is complete, data are delivered to a focal point lead, who enters it into the database.

The focal point lead consults regularly with the CCG and academic partners to address challenges with, and highlight best practices in the data collection process.

After data are collated and analyzed, the results are used to inform targeted advocacy actions.

Because data is being routinely collected, CTOs can monitor trends within the health system over time. This allows activists to document availability, continuity and quality of HIV treatment and service delivery, issue alerts if ARV stock levels become low, identify management issues and develop recommendations for improvements.

CTO data can be shared with key relevant 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 supporting treatment programs in the country—and in reports disseminated by the CTO’s communication platforms.

For a comprehensive guide on CTOs, download our complete CTO Model publication: How Communities Can Collect Health Data to Ensure Accountability and Drive Change. In the report we describe in detail the structure, operational flow, purpose and benefits of a CTO. We also explain how CTOs inform HIV treatment advocacy and illustrate how they can be operationalized in various contexts, drawing lessons from the case study of our Regional Community Treatment Observatory in West Africa.
FIGURE 1
Community Monitoring Along the HIV Continuum of Prevention, Care and Treatment.

How are structural barriers, such as stigma and discrimination, addressed?

FIGURE 2
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.

Academic Institution

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

Data collector

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

Note: The number of data supervisors and data sites shown here are for example only. In operation, these numbers may vary.
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. They play a key role in monitoring HIV services and informing advocacy strategies and 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, sex workers, people who inject drugs).

CTO data can be used to:
- Supplement national health management information system 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 otherwise not included in government reports.
- Provide better insights on access and quality of treatment and services along the HIV cascade, which can be used to identify, prioritize and respond to such gaps.
- Provide insights for communities to develop demand creation strategies, which often play a critical role linking people to services.

Successfully implemented CTOs also empower PLHIV to advocate for access to optimal HIV services by:
- Increasing knowledge among PLHIV and key populations about WHO recommendations, guidelines and quality standards for HIV prevention, testing, care and treatment services, and how to monitor service delivery.
- Building an evidence base from communities highlighting issues related to availability, access, acceptability and 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, program design, and implementation).

ITPC has developed a minimum set of standards to ensure that CTOs operating as part of its community monitoring initiatives are functional, responsive, and beneficial to the communities they seek to support. The accreditation standards cover aspects of governance, national integration, organizational management, data management, and technical capacity.

As the CTO begins its work, the implementing team reviews the operational plan and performance framework to ensure it is operating according to these standards. This is an ongoing process that should happen annually and involves the network of community members and the CCG.

Creating and operating a CTO requires significant investments of time and resources. Based on ITPC’s experience, the costs for establishing and implementing a CTO can range between US$100,000 – 150,000 annually. From the beginning, sustainability must be considered to ensure that the CTO can function effectively, efficiently, and fulfill its intended purposes.

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. CTOs have been adapted to monitor specific aspects of HIV care, as well as to broadly monitor a wide range of issues. 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.
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.

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

ABOUT WATCH WHAT MATTERS
Watch What Matters is a community monitoring, research and advocacy initiative that gathers 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.

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

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