

# HOW TO IMPLEMENT COMMUNITY-LED MONITORING

A Community Toolkit

# TABLE OF CONTENTS

Purpose of the toolkit	4
Definition of CLM	7
Principles of CLM	8
CLM model explained and implemented by quadrant	10
Education	11
Evidence	12
Engagement	15
Advocacy	15
Categories and scale of CLM	18
Structure and roles of the CLM model	19
Technology integration	22
Guiding principles of data management	27
Resourcing and financing of CLM	38
Annexes	40
<b>A</b> UNAIDS, Global Fund and PEPFAR definitions of CLM	41
<b>B</b> Menu of quantitative and qualitative indicators for HIV-focused CLM and related advocacy	44
<b>C</b> Community treatment observatory case studies	48
1) RCTO-WA case study	48
2) CTO COVID-19 adaptation	54
3) CLM approaches in Namibia	67
<b>D</b> CLM and community and institutional systems strengthening	59
<b>E</b> Accreditation process	61
<b>F</b> Resource list	64

# ABBREVIATIONS

<b>AIDS</b>	Acquired immune deficiency syndrome
<b>ART</b>	Antiretroviral therapy
<b>ARV</b>	Antiretroviral
<b>CBM</b>	Community-based monitoring
<b>CCG</b>	Community consultative group
<b>CCM</b>	Country Coordinating Mechanism
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CLM</b>	Community-led monitoring
<b>CSO</b>	Civil society organization
<b>CBO</b>	Community-based organization
<b>COVID-19</b>	Coronavirus disease 2019
<b>CTO</b>	Community treatment observatory
<b>DSD</b>	Differentiated service delivery
<b>Five As</b>	Availability, accessibility, acceptability, affordability and appropriateness
<b>HIV</b>	Human immunodeficiency virus
<b>HTS</b>	HIV testing services
<b>IRB</b>	Institutional Review Board
<b>ITPC</b>	International Treatment Preparedness Coalition
<b>M&amp;E</b>	Monitoring and evaluation
<b>MoH</b>	Ministry of health
<b>MoU</b>	Memorandum of understanding
<b>NACP</b>	National AIDS Control Programme
<b>NETHIPS</b>	Network of HIV Positives in Sierra Leone
<b>PEPFAR</b>	US President's Emergency Plan for AIDS Relief
<b>PEP</b>	Post-exposure prophylaxis
<b>PPE</b>	Personal protective equipment
<b>PrEP</b>	Pre-exposure prophylaxis
<b>RCTO</b>	Regional Community Treatment Observatory
<b>RCTO-WA</b>	Regional Community Treatment Observatory in West Africa
<b>TB</b>	Tuberculosis
<b>U=U</b>	Undetectable equals Untransmittable
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>WAHO</b>	West African Health Organization
<b>WHO</b>	World Health Organization

**COMMUNITY-LED MONITORING (CLM)** uses the power of people living with HIV and key populations to transform information on health systems into life-saving advocacy campaigns. It rapidly generates data on HIV prevention and treatment services and empowers communities to use their findings to identify and advocate for solutions that break down barriers to human rights, better health and higher quality of life.



## PURPOSE OF THE TOOLKIT

This is a how-to guide developed for community organizations that are planning to implement community-led monitoring (CLM). It provides an overview of CLM and steps for designing, implementing, running and resourcing it.

CLM is an integral part of the Global AIDS Strategy Framework 2021-2026,<sup>1</sup> which puts people at the centre of the HIV response and unites countries, communities and partners to:



**1 Maximize equitable and equal access to comprehensive people-centred HIV services**



**2 Break down legal and societal barriers to achieving HIV outcomes**



**3 Fully resource and sustain HIV responses and integrate them into systems for health, social protection and humanitarian settings**

(1) [reliefweb.int/sites/reliefweb.int/files/resources/global-AIDS-strategy-2021-2026\\_en.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/global-AIDS-strategy-2021-2026_en.pdf)

## 2025 HIV TARGETS

**< 10%**

**LESS THAN 10%**  
of people living with HIV and key populations experience stigma and discrimination

**LESS THAN 10%**  
of people living with HIV, women and girls and key populations experience gender-based inequalities and gender-based violence

**LESS THAN 10%**  
of countries have punitive laws and policies



**> 95%**

**95%** of people at risk of HIV use combination prevention

**95-95-95%** HIV testing, treatment, & viral suppression among adults and children

**95%** of women access sexual and reproductive health services

**95%** coverage of services for eliminating vertical transmission

**90%** of people living with HIV receive preventive treatment for TB

**90%** of people living with HIV and people at risk are linked to other integrated health services

**SOURCE:** End Inequalities. End AIDS. Global AIDS Strategy 2021- 2026. UNAIDS 2021. Available at [www.unaids.org/sites/default/files/media\\_asset/global-AIDS-strategy-2021-2026\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/global-AIDS-strategy-2021-2026_en.pdf)

CLM may be used to track a range of issues. Examples are whether and to what extent stigma has made it difficult for people to access HIV services, the proportion of people who have been denied access to HIV prevention and testing, and the number of people who have discontinued antiretroviral therapy (ART) – and the reasons for this. This evidence is fed back to programme managers and policy makers, which enables them to increase the “five As” (availability, accessibility, acceptability, affordability and appropriateness) and the efficiency and effectiveness of HIV services.

The community-led monitoring and advocacy approaches of the International Treatment Preparedness Coalition (ITPC) are designed to put people living with HIV, their communities, networks and/or organizations at the centre of decision

making. Since 2015, ITPC has monitored supply chain management issues and medicine stock-outs, initially in South Asia, eastern Europe and central Asia. This initiative was expanded from alert systems and stock-out monitoring to fully-fledged community-led monitoring programmes. Under ITPC’s strategic pillar, Watch What Matters, CLM approaches (previously known as community treatment observatories, or CTOs) were implemented in West Africa (Benin, Côte d’Ivoire, The Gambia, Guinea, Guinea Bissau, Liberia, Mali, Senegal, Sierra Leone and Togo), Democratic Republic of Congo, southern Africa (Malawi, Zambia and Zimbabwe), Asia (India, Indonesia and Nepal) and Latin America (Guatemala).

ITPC has recently extended its CLM technical assistance programme to civil society organizations in West and

## KEY AREAS OF CLM



---

### CLM is community-led and community-driven.

---

Central Africa, East Africa and the Caribbean, with the support of the Joint United Nations Programme on HIV/AIDS (UNAIDS). It has also extended other CLM technical assistance, with support from the Global Fund to Fight AIDS, Tuberculosis and Malaria in the Caribbean, Eastern Europe and Central Asia (2021-2023). In 2020-2021, with funding from UNAIDS, ITPC rapidly implemented short-term CLM and advocacy during the COVID-19 pandemic in five countries. ITPC has applied the CLM model across several disease areas, collecting data on human rights violations and treatment access gaps in HIV, tuberculosis (TB), human rights, hepatitis C and COVID-19.

CLM covers four key areas: **education**, **evidence**, **engagement** and **advocacy**. It is grounded in education and based on human rights, including the right to health, to ensure that all people are aware of the standard of care they are entitled to receive, as per current World Health Organization (WHO) guidelines for prevention, testing, care and treatment for HIV, TB, COVID-19, viral hepatitis and other relevant conditions.

CLM is community-led and community-driven. It increases accountability for, and improves outcomes of, national and local HIV programmes — and the health of community members.



# DEFINITION OF CLM

**CLM is a process in which communities, particularly people who use health services, take the lead in identifying and routinely monitoring the issues that matter to them.** They create indicators to track prioritized issues, undergo training to collect data and analyse results, and engage with a larger group of stakeholders to share insights from the data and co-create solutions. When problems uncovered through CLM cannot be resolved, communities conduct evidence-based advocacy and campaigns until corrective actions are implemented by those responsible. CLM also documents positive innovations and effective practices that can be implemented with greater consistency and scale (for additional information about and definitions of CLM, see *Annex A, UNAIDS, Global Fund and PEPFAR definitions of CLM*).

In the context of CLM, “community” refers to people living with and affected by HIV, including people who are members of key populations<sup>2</sup> and other marginalized groups, as well as civil society entities promoting human rights and access to care for people living with and affected by HIV.

Communities play an essential role in CLM: they have access to “insider” knowledge and unique experience and perspectives that are not available to external actors. Communities have a central role in ensuring access to health services, improving their quality and holding decision makers accountable. This role is

gaining visibility and is increasingly promoted as an important part of the HIV response. (See *Annex A for a summary table of CLM approaches, as defined by key donors and for various examples of community data*.)

The CLM landscape has continued to evolve, as have needs for clearer definitions and guiding principles to ensure that this work is community-led and advocacy-based. As the notion of CLM becomes more widespread, any feedback mechanism from recipients of care could be misidentified as CLM, instead of the model described in this toolkit.

(2) Key populations are groups of people who are more vulnerable to acquiring HIV and/or have high HIV rates (gay and bisexual men and other men who have sex with men, sex workers, people who use drugs and transgender people) and face high levels of stigma, discrimination and legal, socioeconomic, cultural and structural barriers to accessing health services.



# PRINCIPLES OF CLM

**The increased demand for and interest in implementation of CLM calls for consistent, clear principles. CLM and related advocacy is:**

- **Community-led and community-owned**
- **Focused on action and accountability**
- **Independent**
- **Routine and systematic**
- **Focused on results**

Communities are leaders of, and equal partners in, CLM. It is responsive to their needs and inclusive of their perspectives and preferences. Action and accountability are essential to CLM and related advocacy.

CLM interventions are independent of, and not directed by, governments or donors. They are specifically informed and implemented by — and for — communities and their organizations, groups and networks. They are also collaborative and intended to engage multiple stakeholders in co-creating and implementing solutions, instead of assigning blame.

CLM interventions show measurable results: an increase in the number of people on continuous ART; higher

rates of viral suppression; and a decrease in stock-outs of drugs and testing supplies. The ultimate goal is improving the health, quality and length of life of people living with and affected by HIV.

**CLM interventions are also sustained over time:**

- a) To provide up-to-date evidence for health facility managers, government health officials and other decision makers
- b) To foster change through cycles of successive achievements or setbacks and through processes of gaining audiences, allies and constituents, if needed, for credibility and influence



## KEY CONSIDERATIONS TO SUSTAIN THE CLM APPROACH

- 1 Funding of and investment in CLM.** There is a need to ensure adequate availability of funds to implement CLM and related advocacy interventions. The scale of the CLM approach should match the available budget (the number of sites and indicators selected has an impact on the budget).
- 2 Integration of the CLM approach into national strategic plans or other national policy frameworks or country investment plans.** There is a need for CLM to be adopted as a key community intervention that contributes to the national response.
- 3 Capacity building and accreditation of CLM implementing partners.** Investment in training and institutional systems strengthening of civil society organizations (CSOs) is critical to ensure the capacity to implement CLM.
- 4 Ownership of CLM by communities and CSOs.** It is essential to ensure that CLM is truly community-led and supported by national structures.
- 5 Community consultative groups (CCGs) and/or district or national structures.** It is necessary to create mechanisms for feedback and dissemination of data to realize advocacy outcomes. It is critical to have national or district platforms where solutions can be co-created to alleviate treatment and service gaps and improve quality.
- 6 Ethical clearance and/or authorization for data collection.** CLM implementers need ready access to data at health facilities and should be able to conduct focus group discussions.
- 7 Data quality assurance.** The CLM approach will be compromised if the wrong data are used. Mechanisms must be put in place to ensure data accuracy and integrity.

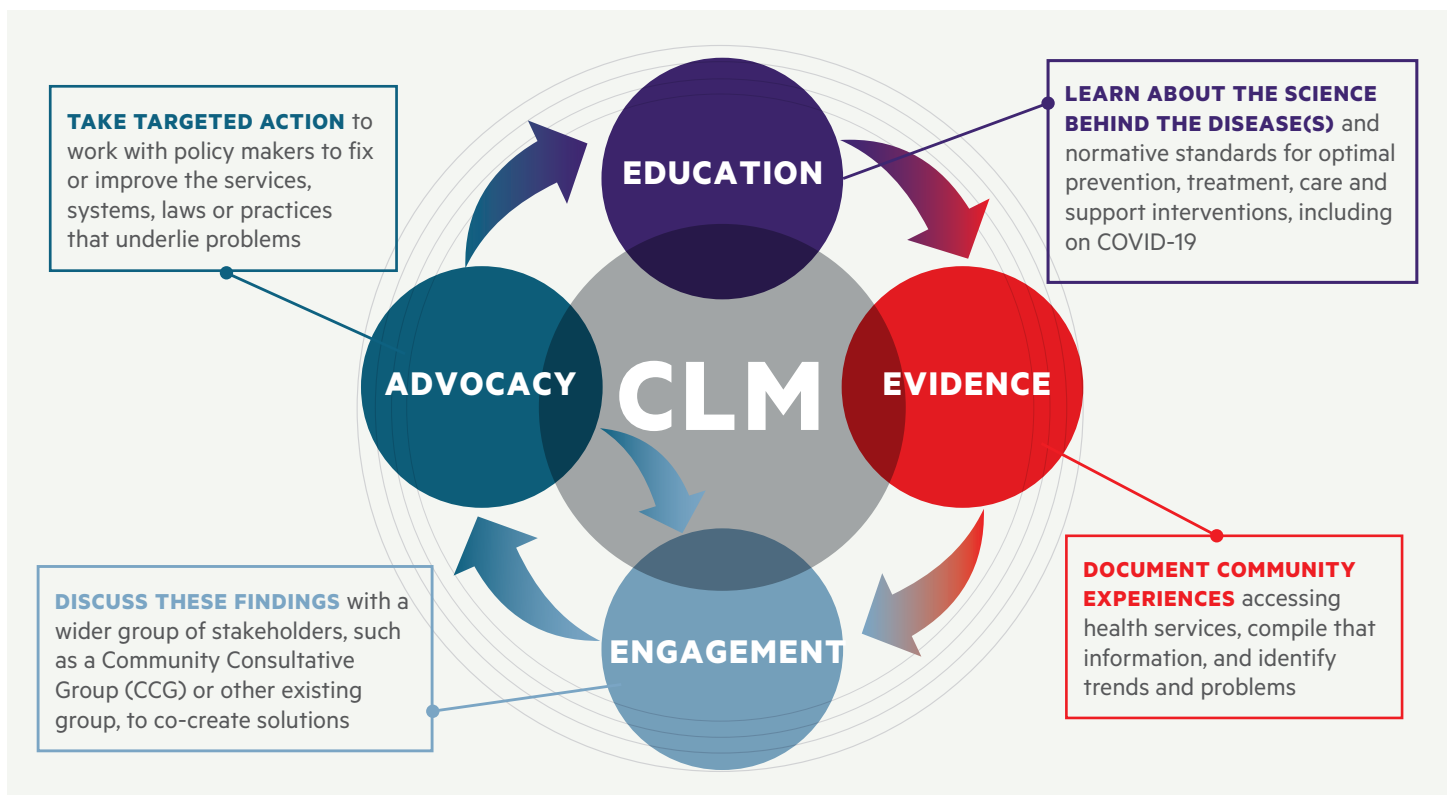


# CLM MODEL EXPLAINED AND IMPLEMENTED BY QUADRANT

Community-led organizations perform CLM. These host organizations/CLM implementers oversee and fulfil work within the four key quadrants of CLM: **education, evidence, engagement, and advocacy**. Each quadrant has specific objectives and corresponding interventions which build upon each other. All four quadrants must be fully implemented for successful CLM.

People involved with CLM will gain an understanding of how to collect and secure data and what they are monitoring: what to collect, why it matters, and how it will be used.

**FIGURE 1** ENGAGEMENT and ADVOCACY are mutually reinforcing and cyclical



# Education

**Education** builds a strong, sustainable foundation for organizations that host CLM and related advocacy and benefits the people who provide it. ITPC’s trainings support community and institutional systems strengthening by covering focus areas, such as monitoring and evaluation (M&E) methodologies, governance, finance and grant management. Since the implementing organization’s capacity and health are critical to the success of CLM, host organizations undergo accreditation processes and capacity assessments to inform training needs. Data collectors and supervisors learn standardized procedures for collecting, storing and securing data to assure consistency across sites; they are also trained on qualitative and quantitative methods for carrying out their work and understanding why the data they are collecting matters.

Advocacy-focused CLM staff and stakeholder trainings are developed based on community priorities and a

capacity assessment. These trainings are grounded in human rights, highly interactive and directly linked to indicators selected by communities. As an example, a CLM approach focused on HIV would include: education around HIV transmission; the cascade of prevention, testing, care and treatment, including optimized ART; service delivery; viral load monitoring; and human rights issues. These trainings ensure that community members understand the services and treatment they are entitled to and are familiar with their national treatment guidelines. They also build knowledge of standards for competency and quality for routine health screenings and testing services, medical care and treatment, and prevention and support services in the context of current targets, declarations and internationally recognized standards for HIV treatment and services (notably, Fast-Track, UNAIDS 95-95-95 targets, Sustainable Development Goals and WHO guidelines). This provides the foundation for effective advocacy.

**TABLE 1 Elements of CLM: HIV education and their purpose**

TRAINING AREA	CONTENT	PURPOSE
<b>HIV transmission</b>	Explanation of how HIV is transmitted	Underscore the importance of access to HIV prevention and treatment.
<b>HIV prevention</b>	Overview of WHO-recommended combination HIV prevention	Document gaps in access to WHO-recommended combination HIV prevention, including male and female condoms, pre- and post-exposure prophylaxis (PrEP and PEP), the dapivirine vaginal ring, needles, syringes and other equipment for using drugs, and opioid substitution therapy.
<b>HIV testing</b>	Describe process and WHO-recommended HIV testing options	Document gaps in access to WHO-recommended testing methods, including self-testing, and whether services are adapted to the needs of key populations.
<b>HIV natural history</b>	Outcome of untreated HIV – progression from acute infection to advanced HIV disease, illness and death and continuing transmission	Gain an understanding of the importance of access to HIV testing, care and treatment.

TRAINING AREA	CONTENT	PURPOSE
<b>HIV treatment</b>	Overview of the goal of HIV treatment and WHO-recommended ARVs for first-, second- and third-line treatment: how they work and what they do (including side-effects and adverse events)	Gain understanding of why access to HIV treatment is essential for survival, health and quality of life among people living with HIV (and its prevention benefit), as well as which ARVs should be available.
<b>Treatment adherence/ drug resistance</b>	Importance of adherence; consequences of poor adherence	Gain an understanding of the importance of access to HIV testing, care and treatment.
<b>Monitoring HIV treatment outcomes</b>	What is viral load monitoring? WHO recommendations for monitoring HIV treatment outcomes. What results mean (U=U, treatment failure, adherence support, switching ARV regimen)	Document understanding of, access to and frequency of viral load testing (including timely results) and actions triggered by viral load test results.
<b>Common co-infections</b>	Transmission and outcomes of TB and viral hepatitis; WHO-recommended testing, prevention, care and treatment	Document access to, quality of and user fees for prevention, testing, care and treatment for TB and viral hepatitis.
<b>Human rights/right to health</b>	Stigma and discrimination and their impact on health care uptake and health outcomes	Document and address stigma and discrimination competency in health care settings.

## Evidence

Community data is the **evidence** that informs advocacy. Gathering this evidence is often the most visible component of CLM. It involves situational analysis and mapping processes, securing and collecting data, verifying, entering and cleaning it, data analysis (including monitoring for trends), and data quality audits. Each of these steps is explained in more detail here:

- **Conduct baseline assessment.** The CLM staff should conduct a baseline assessment of all quantitative and qualitative indicators. Over

time, the data they collect can be compared with baseline assessments to monitor trends and track improvements (or declines) in treatment access and service quality.

- **Data collection.** Data collectors use data collection tools at each site as often as specified in the final operational plan (for example, 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 have been verified, data supervisors deliver it to the focal point lead or another 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 good practices and/or challenges in the data collection processes — in parallel, they look at systems that can be used to problem-solve and provide follow-up on advocacy.
- **Data management and storage.** If data are being collected with a standard paper-based form and/or questionnaire, the operational plan should outline standard procedures for safeguarding, storing and/or discarding them after they have been entered into the computer's database. The procedure for storing or discarding paper forms should comply with Institutional Review Board (IRB) protocols to ensure safeguarding of sensitive and/or identifying information. Physical forms, questionnaires, notes from meetings and any

other reports from interviews and focus group discussions should be stored in locked cabinets. Documents may also be scanned and uploaded to a central database as backup to minimize data loss and enhance data security. If data are being collected electronically, management procedures should ensure that they are recorded and stored in standardized formats to ensure consistency for ease of access, reviewing, analysis and reporting.

- **Data review and analysis.** After data are entered into the database, the CLM 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 lead (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: Are the data demonstrating progress towards targets? Is it possible to link data to any outcomes? Which data are most useful for advocacy? Are there any indicators for which data have 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? Depending on the capacity of the CLM implementer, an academic or research institution or other experts can provide assistance with data analysis and/or performing data quality audits to ensure their validity. Universities and research institutions have often supported CLM implementers to develop the data analysis frameworks, train and perform data analysis and/or conduct data quality audits to refine the indicators and/or data collection methods.

- **Data quality audit.** In addition to the routine data quality review and analysis conducted by the data supervisor(s) and focal point lead, it is critical to conduct formal data supervision and quality assessments. This process involves field visits, where the implementing team can troubleshoot any issues that would lead to inaccurate, incomplete and/or unreliable data.

## Snapshot of regional advocacy priorities

Advocacy priorities for the RCTO-WA, set by the Regional Advisory Board in October 2018

### By 2020, 90% of people living with HIV will know their status

- Expand the availability of **non-facility-based HIV testing options**, including community-led and community-based HIV testing services (HTS)
- Intensify HIV communication and awareness campaigns to **increase demand for HTS**
- Include objectives to **promote and protect human rights** of people living with HIV and key populations in **costed HIV strategic plans**

### By 2020, 90% of people living with HIV will know their status and will be receiving sustained ART

- Improve communication along the **supply chain to prevent stock-outs** of antiretrovirals
- Enhance **linkage to — and retention in —** care and treatment, especially for key and vulnerable populations
- Strengthen community systems and responses to support the roll out of differentiated service delivery

### 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
- Enhance knowledge among people living with HIV and healthcare workers to **increase demand for high-quality viral load testing services**
- Ensure effective treatment monitoring through acceptable **turnaround times for viral load test results**

# Engagement

## Why engagement matters

CLM stakeholders are representatives from networks of people living with HIV, including key populations, officials from health care facilities and ministries of health, policy makers and academic partners; all are invested in achieving the best possible outcomes from national AIDS programmes. Thus, CLM is an effective way to solve problems collaboratively.

**Engagement** develops from partnerships between a variety of stakeholders; it increases the visibility and impact of advocacy. Engagement provides communities and health care providers with a platform for convening and sharing data to facilitate improved health outcomes for recipients of care.

Engagement facilitates collaboration in identifying, implementing and sustaining solutions, and furthers government investment in, and accountability for, improving the reach and quality of HIV services and their delivery. For example, CLM implementers can organise meetings with health facilities and/or district and national decision makers, where data are reviewed and solutions are co-created to mitigate identified gaps in treatment and service delivery.

CLM and related advocacy engagement is facilitated through a community consultative group (CCG),

which is a multistakeholder technical advisory board that provides essential support. The CCG is made up of representatives from national networks of people living with HIV, key populations, and recipients of care. The CCG contributes data collection tools, supports implementation of CLM, helps with data analysis, and gives direction on organizational decisions. The CCG also creates an evidence-based advocacy agenda. It meets on a monthly or quarterly basis to review data that have been cleaned, validated and analysed and to prioritize advocacy issues. During CCG meetings, communities and decision makers strategize on ways to address issues and solve problems. This process is the framework for collaboration since relationship-building enhances effectiveness of work between stakeholders who are mutually invested in positive health outcomes for their communities and their programmes.

## Advocacy

The purpose of HIV CLM is to improve access to and quality of HIV treatment and services through evidence-based **advocacy** and to identify innovations and good practices that can be sustained, replicated and brought to scale.

When data collection reveals gaps in access to and quality of services, stock-outs of medicines, laboratory supplies and other essential commodities and other problems (the evidence), community members advocate for solutions to these issues.

Evidence-based advocacy uses targeted actions to change norms, guidelines, standards and policies that directly affect the health of people living with and at risk for HIV. This advocacy is aimed at improving individual and community health outcomes at local, subnational, national, regional and global levels. Table 2 provides examples of successful CLM.

When it is not possible to co-create solutions, communities and treatment activists often forge ahead to address their needs and hold decision makers

accountable, using watchdogging and/or participatory monitoring and accountability approaches. As an example, the Initiative for Equity uses participatory citizen monitoring and accountability as a method for “... effective involvement by community members in the decisions that affect their lives. Rather than suffering under poor decisions and implementation by governments, agencies, and businesses, which can be ineffective, corrupt, or actively harmful, it helps community members and civil society groups to gather information, document problems, and insist that laws are followed and promises met. Forming alliances with

other communities and organizations which have the same objectives can help to greatly strengthen the monitoring and accountability outcomes. Participatory monitoring is a well-organized and ongoing activity in which community members and civil society organizations gather information on their analysis and priority issues in a way that answers the essential questions: what are people experiencing? how is it affecting people? is the policy or program working? what are the problems? what could be done better? what are people’s priorities for change?”<sup>3</sup>

**TABLE 2 The power of CLM and related advocacy**

INDICATOR	ADVOCACY	OUTCOMES
<b>Viral load testing in West Africa</b>	Increase community treatment literacy, create demand for, and increase access to, viral load testing.	From mid-2018 to mid-2019, the number of viral load tests increased from 16,532 to 33,376.
<b>Viral load testing in Malawi</b>	Increase frequency of and access to viral load testing.	CLM data were used to advocate for a change in the national guidelines from recommending viral load testing every 24 months to recommending it every 12 months.
<b>Stigma in health care facilities, especially among members of key populations (data collectors who were members of key populations interviewed other key population members and health care workers about stigma)</b>	Address or diminish stigma in health care settings.	Health care workers became sensitized thanks to training provided; members of key populations were informed of their rights during interviews.
<b>ARV stock-outs in Zimbabwe</b>	Determine the cause (s) and work to eliminate stock-outs.	Stock-out duration was reduced by 13 days.
<b>Access to HIV testing and treatment in Côte d’Ivoire</b>	Remove barriers.	User fees for HIV testing and treatment were eliminated.

(3) <https://www.initiativeforequality.org/what-we-do/citizen-monitoring/participatory-citizen-monitoring/>



**“That is the beauty of projects like this.  
They identify how people fall through the cracks.”**

— MARTIN ELLIE, NETWORK OF HIV POSITIVES IN SIERRA LEONE (NETHIPS), SIERRA LEONE

ITPC developed a time- and scope-limited CLM and related advocacy project to monitor access to care and treatment for HIV and TB, as well as health and human rights experiences, among recipients of care over three months in five countries. In Sierra Leone, NETHIPS, one of ITPC’s partner organizations, aimed to collect data on the number of people who experienced ART failure. Within a month of monitoring, NETHIPS discovered that data on HIV treatment failure was not included in current service registers. NETHIPS initiated a conversation with the National AIDS Control Programme (NACP), where it learned that a committee examines treatment failure on an individual basis and records the information on appointment cards. In some facilities, these data are stored separately from the facility’s master register. NETHIPS used the conversation to secure a commitment from the NACP to develop new service registers that include indicators on HIV treatment failure.

CLM and related advocacy go further than research and monitoring and evaluation (M&E) initiatives, which collect and analyse data. CLM and related advocacy link data collection and analysis directly with partnerships for rapid problem solving and advocacy to achieve and maintain solutions.

The interventions of CLM (education and data collection with secure storage, and validation and analysis in the context of multistakeholder engagement) are done with the ultimate goal of informing advocacy to improve health care delivery and health outcomes, which result in better health outcomes for communities.

### **Results from ITPC Regional Community Treatment Observatory (2017-2019)**

ITPC implemented a CLM and related advocacy model (called the Regional Community Treatment Observatory, or RCTO), which united the organizations performing CLM in West and Southern Africa. Three years after the RCTO was implemented across West Africa, stock-outs of ART and laboratory reagents for viral load testing decreased by 8.4% and 10.7%, respectively. At the same time, 23,618 more people were initiated on ART and 16,844 additional viral load tests were performed. During this period, the average rating for quality of care rose from 3.8 to 4.2 (of 5). At the national level, rates of HIV testing and ART uptake increased among key populations in Sierra Leone: treatment monitoring improved among people on ART in Mali; site-level data tracking mechanisms were revised in the Gambia; and user fees, which were a major access barrier to HIV services, were eliminated in Côte d’Ivoire.



# CATEGORIES AND SCALE OF CLM

It is critical to determine the scale and category of CLM based on the budget ceiling, the host organization’s capacity and the timeline for implementation, among other factors. Planners should strive to obtain **a representative sample size**. This depends on the total population size (or the total number of people living with HIV) using the facility (for pilots), in the district (for subnational-level CLM) or in the country (for national-level CLM).

There are **three categories of implementation** that the host organization can assess to determine “right fit”. These are:

- **Pilot/urban-level CLM.** This is small scale and usually implemented in one or two health facilities in an urban area or capital city. For a population of <10,000 people living with HIV, sample at least 20-25% of them.

In some situations, the small size may give the host organization a chance to pilot CLM and build capacity for implementing larger-scale work. Once the pilot is completed, CLM can be scaled up based on such aspects as skills, budget and timeline. However, this category may be the most appropriate for very local-level advocacy and may not require scale up.

- **Subnational-level CLM.** This level of implementation goes across two or three subnational areas (for example, districts, provinces and regions), collecting data from a population of 10,000-100,000 people living with HIV and sampling at least 10-15% of them. Data can be collected from up to 50 health facilities, based on aspects such as skills, budget and timeline.
- **National-level CLM.** Data can be collected from 51+ health facilities, based on aspects such as skills, budget and timeline. A national CLM and related advocacy model works for a population of >100,000 people living with HIV, sampling at least 3-5% of them.



# STRUCTURE AND ROLES OF THE CLM MODEL

## Structures

**The following structures are required to implement CLM:**

**The host organization or CLM implementer or community network.** CLM should not be built as a standalone project. To create a solid and sustainable foundation for CLM, it should be embedded in, and owned by, an existing organization. This will ensure that CLM is integrated within the larger system.

**Data collection sites.** Data can be collected at public and/or private health facilities, community-based service delivery facilities and/or community service points (for example, community groups).

Data collection sites are determined by factors such as urban versus rural, HIV prevalence, volume of recipients of care, large hospital versus community centres, and willingness to participate. Once sites are selected, a formalized partnership should be established between the host/community organization and the site via a memorandum of understanding (MoU) or other working agreement. Depending on the type of site (for example, public health facility), it may also be necessary to establish a working agreement with the MoH to ensure that the host organization will be able to access and collect data as needed.

## Community-led organizations

Community-led organizations, groups and networks, whether formally or informally organized, are entities:

- **For which the majority of governance, leadership, staff, spokespeople, membership, and volunteers, reflect and represent the experiences, perspectives, and voices of their constituencies**
- **Who have transparent mechanisms of accountability to their constituencies**

Community-led organizations, groups and networks are self-determining and autonomous, and not influenced by government, commercial or donor agendas.

Not all community-based organizations are community-led.

## The implementation team

**CLM requires a team to oversee and facilitate its implementation. At a minimum, the team should include (and provide financial support for):**

**Focal point lead.** This person has oversight of CLM implementation. The focal point person will also facilitate community consultative group (CCG) meetings, dialogues with sites, work with health officials to ensure that formal agreements for data collection are in place, ensure project visibility, and ensure national ownership of the project, and that insights from data are used for targeted advocacy.

**M&E officer.** The M&E officer has oversight of community data collection, management, analysis and verification processes. The M&E officer is responsible for overseeing capacity-building, providing technical support on data collection and management processes for data supervisors and data collectors, developing and reviewing reports generated from community data before they are disseminated to the CCG and external stakeholders, distilling data insights from country-level reports to macrolevel, and general data management oversight.

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

**Data collectors.** Each data collector is responsible for collecting data from specific sites. Data collectors interact directly with 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 need to visit data sites only once a month for quantitative data, it could be feasible — and more efficient — to have one data collector cover multiple sites.

## Technical advisory groups

**A pair of technical advisory groups support the host organization, CLM implementer and community network in implementing CLM:**

**Academic institution.** A partnership with an academic institution should be formalized through an MoU or contract. Such a partnership is invaluable for building capacity among community members who are implementing CLM. Ideally, a local academic partner will provide ongoing technical assistance, including helping to develop the data collection tool, performing data analysis and data quality audits. Academic institutions can also facilitate ethical processes, work with an IRB and assist with publishing and

disseminating 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 and technical agencies) can support these processes.

**Community consultative group.** To ensure that CLM is responsive to the community and its needs, the implementing network must set up and collaborate with a CCG. The CCG supports CLM implementation, contributes to development of data collection tools, helps with data analysis, and gives direction on organizational decisions. The CCG is comprised of key

stakeholders. These include representatives of civil society organizations, national networks of people living with HIV and key populations, health care facilities, recipients of care, staff from UNAIDS country offices and regional support teams, and other funding partners, such as the US President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund, as well as high-level decision makers (from the MoH and national AIDS programme, for example). The CCG serves three purposes:

- 1. Reviewing and analyzing collected data**
- 2. Developing an advocacy agenda (based on validated data) and identifying strategic opportunities to facilitate advocacy actions**
- 3. Finding and leveraging opportunities to sustain CLM beyond current grant funding**

The CCG identifies advocacy priorities and develops an action plan, which includes monitoring and assessing the impact of trends and changes. The CCG is responsible for:

- Reviewing and endorsing data (using established data verification processes)
- Providing technical and strategic guidance to improve the data collection process in partnership with academic partners or independent experts
- Identifying advocacy agendas and/or issues and developing an evidence-based advocacy plan
- Supporting the implementing partner in building the visibility of CLM and related advocacy
- Accessing national policy and political forums with the host organization to present and integrate data into health information policies and systems
- Supporting the host organization in implementing the advocacy plan and actions
- Supporting the implementing partner to mobilize resources for sustaining CLM and related advocacy beyond the current grant funding

## **Composition of the community consultative group**

The CCG has 10-15 members, including a chair, a vice-chair and members from these categories:

- **Normative agencies.** This can include UNAIDS, PEPFAR, WHO and the Global Fund.
- **Government organizations.** This can include representatives from the national AIDS and/or TB programmes and other government counterparts.
- **Civil society organizations.** This can include strategic partners from civil society organizations.
- **Partners.** This can include target populations, members of key populations and national people living with HIV networks.
- **Research institute or independent expert.** People with relevant expertise can be invited to join the CCG.

The host organization acts as the CCG secretariat.

**Confidentiality:** All data presented in CCG meetings or that CCG members have access to is confidential. Any external use or discussion of data requires prior authorization from the CCG chair.

**Methodology:** The CCG meets monthly after academic partners or independent experts have completed data quality review and analysis. When possible, meetings should be face to face (due to COVID-19, meetings could be held virtually).

Depending on the circumstances, external experts can be invited to CCG meetings to provide advice and guidance on data interpretation and maximizing the impact of evidence through advocacy.



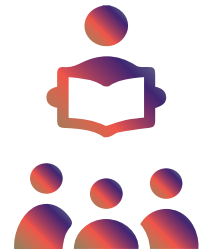
# TECHNOLOGY INTEGRATION

## The role of technology in the data journey

When you think of CLM and the data it captures as a story, you will have a better idea of how technology can be harnessed to help you tell that story. You might try thinking of data as a character in your story, and then think of the best way to take care of your cast (see Figure 3).

### ACTIVITY: TELL ME A STORY

When determining how technology can be integrated into CLM, the first step is to ask yourself, “What am I trying to communicate?”



1

#### **Define the main premise.**

Think of your audience and decide what you want them to know or remember.

2

#### **Plan the script and the narrative.**

For your audience to know or remember your main premise, what do they need to see or hear? Consider the need for a script, text or audio to convey your message.

3

#### **Identify supporting media.**

What do you want your audience to see, sense or feel? For this, think about the possible need for pictures, videos, graphs, tables, quotes or interactives.

**FIGURE 2 Considerations for technology use in CLM: Amplifying your story**

 <p><b>PURPOSE</b></p> <ul style="list-style-type: none"> <li>→ Why are we gathering data?</li> <li>→ What is it meant to show us?</li> <li>→ What will it track?</li> <li>→ How can we use what we find?</li> </ul>	 <p><b>SUBJECT</b></p> <ul style="list-style-type: none"> <li>→ Who are we surveying?</li> <li>→ Who are we not surveying?</li> <li>→ How will we reach them?</li> <li>→ Are we authorized to survey them?</li> </ul>	 <p><b>AUDIENCE</b></p> <ul style="list-style-type: none"> <li>→ Who are these data for?</li> <li>→ Should they be restricted or available for everyone (open data)?</li> <li>→ Rules on permissions and access?</li> </ul>
 <p><b>TYPES</b></p> <ul style="list-style-type: none"> <li>→ What kind of data are we gathering?</li> <li>→ Text, numbers, audio, video, location, behaviour?</li> <li>→ Are we interested in what people do (activity) and how they think (motivations)?</li> </ul>	 <p><b>COLLECTION</b></p> <ul style="list-style-type: none"> <li>→ How will we collect the data?</li> <li>→ How will we organize the data?</li> <li>→ How will we transfer the data?</li> </ul>	 <p><b>STORAGE</b></p> <ul style="list-style-type: none"> <li>→ How will we store the data?</li> <li>→ Where will we store the data?</li> <li>→ Do we need backups?</li> <li>→ How long do we keep the data?</li> </ul>
 <p><b>SECURITY</b></p> <ul style="list-style-type: none"> <li>→ Can the data put anyone at risk?</li> <li>→ How do we keep everyone safe?</li> <li>→ What info do we NEED and what do we NOT need?</li> <li>→ What info can we anonymize?</li> <li>→ What protocols are in place in case of a breach?</li> </ul>	 <p><b>USAGE</b></p> <ul style="list-style-type: none"> <li>→ Who will use this data?</li> <li>→ How will they use it?</li> <li>→ Who will use what they made with the data?</li> <li>→ Do we need to track usage?</li> </ul>	 <p><b>OWNERSHIP</b></p> <ul style="list-style-type: none"> <li>→ Who owns the data?</li> <li>→ Who can access it?</li> <li>→ When can they access it?</li> <li>→ What stage will data be accessible?</li> <li>→ Do ownership rights expire?</li> </ul>

Next, follow the “data journey” in Table 3 to see what kind of technology you need at different steps in the process. **The data journey spans six main phases:**

## MAIN PHASES OF THE DATA JOURNEY

- 1 Concept and configuration.** Plan indicators and questions, expected responses and potential insights and/or trends. This planning exercise will ensure that the team knows what information it is collecting and how they will be expected to use it. Technology infrastructure setup and training also occur at this point.
- 2 Capture and collection.** Data collectors embark on their mission, armed with their recording tools (paper worksheets for written data and responses, mobile device for photos, and audio recordings.) All assets collected will be appropriately prepared (including scanned, exported, transcribed and summarized) for the next phase. Mobile phones are preferable to tablets in the field because phones are :
  - Smaller and more discrete, reducing the risks of data collectors becoming targets of security enforcers or other bad actors who may want to confiscate their devices
  - Better equipped with noise-cancelling technology for audio recordings of interviews
  - More appropriate for use since data collectors will not be showing the content to interviewees (in which case a larger screen would be helpful for shared review)
  - More familiar to data collectors, so they will require less training to use than tablets or other devices
  - Equipped with high-quality cameras for contextual photos (not of individuals) and document scanning (as part of the data collection process)
- 3 Review and verification.** CLM data supervisors will receive and collate data and verify that the collected data meet quality checks and are labelled properly before final packaging and secure submission to a secured data portal (via computer). The portal will be the primary datastore/ source for all CLM and related advocacy records.
- 4 Analysis and evaluation.** Once available in the portal, the analysis team will be able to access and evaluate the data that have been collected. Team members will be allowed to extract a copy of the available data and will be expected to submit and link/upload any processed outcomes back onto the portal (attributing the relevant source to the derivative product or report).
- 5 Reporting and distribution.** The analysis team will communicate with the CLM team about any adjustments or preliminary findings on an ongoing basis. Additionally, any completed reports will be available on the portal for the CLM team, so that they remain aware of emerging findings.
- 6 Advocacy and implementation.** The outcomes from the analysis and reporting can be crafted into appropriate messages, evidence and visualizations that can be used to support advocacy and implementation efforts from civil society and partners.



# THE DATA JOURNEY

**TABLE 3**

The phases of CLM and how different technologies can be integrated along the way

CONCEPT & CONFIGURATION	CAPTURE & COLLECTION	REVIEW & VERIFICATION	ANALYSIS & PATTERN RECOGNITION	REPORTING & DISTRIBUTION	ADVOCACY & IMPLEMENTATION
<ul style="list-style-type: none"> <li>→ Design indicators for observation</li> <li>→ Confirm data format for analysis</li> <li>→ Consider data format for capture</li> <li>→ Consider data transformations needed</li> <li>→ Consider data journey, transfer and storage</li> <li>→ IRB clearance</li> <li>→ Team training</li> </ul>	<ul style="list-style-type: none"> <li>→ Record quantitative data on worksheets</li> <li>→ Record qualitative data (key insights, quotes) on worksheets</li> <li>→ Record qualitative interviews on audio recordings</li> <li>→ Capture photos of facilities, completed worksheets, physical context of location (but not people)</li> </ul>	<ul style="list-style-type: none"> <li>→ Translate and transfer data from worksheets into digital tool</li> <li>→ Complete required data fields on digital form</li> <li>→ Capture question responses, key insights and quotes on digital tool (with timecode references)</li> <li>→ Upload/update audio transcription</li> </ul>	<ul style="list-style-type: none"> <li>→ Data notification to analysis team</li> <li>→ Data clean-up and standardization</li> <li>→ Data review and follow up with CLM</li> <li>→ Analysis and insight development</li> <li>→ Review</li> <li>→ Key analysis and notes submission</li> <li>→ Key quotes and timecode recording</li> <li>→ Indexing and tagging</li> </ul>	<ul style="list-style-type: none"> <li>→ Interim feedback to CLM</li> <li>→ Adjustment directions to CLM if necessary</li> <li>→ Creation of interim updates</li> <li>→ Creation of final report</li> <li>→ Creation of shareable assets</li> </ul>	<ul style="list-style-type: none"> <li>→ Advocacy supported by shareable assets (tracked on digital tool where known)</li> </ul>

## DATA SECURITY

<ul style="list-style-type: none"> <li>→ Configure data storage</li> <li>→ Configure data capture format</li> <li>→ Configure data capture tools</li> <li>→ Configure data transfer tools</li> <li>→ Configure data storage and backup</li> <li>→ Configure content and translations</li> <li>→ Test data capture process</li> </ul>	<ul style="list-style-type: none"> <li>→ Collect quantitative worksheets from each data collector</li> <li>→ Collect qualitative worksheets and associated audio recordings from each data collector</li> <li>→ Upload digital version of each item collected</li> </ul>	<ul style="list-style-type: none"> <li>→ Supervisor verification of data entry accuracy</li> <li>→ Collation of submissions for the reporting period</li> <li>→ Update and notification of submissions</li> </ul>	<ul style="list-style-type: none"> <li>→ Cross time period analysis</li> <li>→ Projections and comparisons</li> <li>→ Cross country or other classification analysis and patterns</li> <li>→ Key insights or hypothesis recording</li> </ul>	<ul style="list-style-type: none"> <li>→ Presentation to community consultative group</li> <li>→ Distribution of sharable assets</li> </ul>	<ul style="list-style-type: none"> <li>→ Review of CLM functionality for next phase of data capture</li> </ul>
--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------






## TECHNOLOGY OPTIONS

<ul style="list-style-type: none"> <li>→ Database</li> <li>→ Survey tool</li> </ul>	<ul style="list-style-type: none"> <li>→ Paper</li> <li>→ Tablet</li> <li>→ Mobile</li> <li>→ Mobile data</li> </ul>	<ul style="list-style-type: none"> <li>→ Computer</li> <li>→ Cloud platform</li> <li>→ Wi-Fi</li> </ul>	<ul style="list-style-type: none"> <li>→ Computer</li> <li>→ Cloud platform</li> <li>→ Wi-Fi</li> </ul>	<ul style="list-style-type: none"> <li>→ Computer</li> <li>→ Cloud platform</li> <li>→ Wi-Fi</li> </ul>	<ul style="list-style-type: none"> <li>→ Computer</li> <li>→ Data visualization software</li> <li>→ Digital design</li> </ul>
-------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------

Depending on your data journey, different data collection tools may be preferred. The information in Table 4 can help you choose the right kind of technology for your CLM approach. We recommend weighing the pros and cons of each technology option according to your context.

**TABLE 4**

The right technology tools to support the ideal data journey

	 <b>PAPER</b>	 <b>MOBILE</b>	 <b>TABLET</b>	 <b>COMPUTER</b>
<b>Pros</b>	<ul style="list-style-type: none"> <li>→ Best for rapid note taking</li> <li>→ Not constrained by power or data access</li> <li>→ Familiar interface</li> <li>→ Low cost</li> </ul>	<ul style="list-style-type: none"> <li>→ Discrete</li> <li>→ High-quality photos and video recording</li> <li>→ Content instantly shareable</li> <li>→ Not quantity constrained</li> <li>→ Familiar interface</li> </ul>	<ul style="list-style-type: none"> <li>→ Good for viewing</li> <li>→ Good for typing</li> <li>→ Content instantly shareable</li> <li>→ Not quantity constrained</li> </ul>	<ul style="list-style-type: none"> <li>→ Best for typing</li> <li>→ Best for compiling, reviewing and submitting</li> <li>→ Best for analysis</li> </ul>
<b>Cons</b>	<ul style="list-style-type: none"> <li>→ Limited to quantity available</li> <li>→ Needs to be digitized</li> </ul>	<ul style="list-style-type: none"> <li>→ Difficult typing</li> <li>→ High cost</li> </ul>	<ul style="list-style-type: none"> <li>→ Clumsy for active note taking</li> <li>→ High cost</li> </ul>	<ul style="list-style-type: none"> <li>→ Not very mobile</li> <li>→ High cost</li> </ul>
<b>Dependencies</b>	<ul style="list-style-type: none"> <li>→ Printed</li> <li>→ Safekeeping</li> <li>→ Proper discarding</li> </ul>	<ul style="list-style-type: none"> <li>→ Mobile data</li> <li>→ Battery</li> <li>→ Storage for media recording</li> <li>→ Safekeeping</li> </ul>	<ul style="list-style-type: none"> <li>→ Mobile data</li> <li>→ Battery</li> <li>→ Storage for media recording</li> <li>→ Safekeeping</li> </ul>	<ul style="list-style-type: none"> <li>→ Stable power</li> <li>→ Wi-Fi</li> </ul>
<b>Considerations</b>	<ul style="list-style-type: none"> <li>→ Great in combination with mobile for qualitative data</li> <li>→ Great for quantitative data if, for example, the content source is in a different format (unknown) requiring calculations</li> </ul>	<ul style="list-style-type: none"> <li>→ Great for audio recordings during qualitative interviews</li> <li>→ Great for photos of quantitative data in the health care facility register</li> <li>→ Great for photos of completed paper worksheets as a backup</li> </ul>	<ul style="list-style-type: none"> <li>→ Can be used similarly to a mobile phone (but not as optimal)</li> <li>→ Great for providing content for feedback (watch this video/use this app/view this layout, then answer these questions).</li> </ul>	<ul style="list-style-type: none"> <li>→ Great for planning, collection, transfer and analysis activities</li> <li>→ Acceptable for simple data capture</li> </ul>

General technical support for CLM implementation can be managed via a WhatsApp group. This group may deal with broad questions and clarifications as members work through the phases of the data journey.

Other CLM-specific technical support may be facilitated directly via other communication channels, such as video conferencing, email and calls.



# GUIDING PRINCIPLES OF DATA MANAGEMENT

## Ethics, safety and data protection

CLM often involves collecting highly sensitive, personal information about people’s health and their experiences. People’s privacy and their consent are extremely important to data collection for CLM. Experience with implementing CLM has shown that loss of privacy, confidentiality and security are common reasons for people to avoid using healthcare services. The public health goal of CLM must be carefully balanced with the individual right to privacy and confidentiality.

The first step — before any data are collected — is to ensure participants’ informed consent.

---

**Focus group discussions with young people in ITPC’s RCTO in West Africa underscored the importance of confidentiality and privacy, which emerged as a top reason for not accessing ART.**

---

**TABLE 5**  
**Tips to ensure informed consent of participants in CLM and related advocacy**

BARRIER TO INFORMED CONSENT	HOW CLM AND RELATED ADVOCACY CAN OVERCOME THE BARRIER
<b>Language</b>	Use the person’s mother tongue on the consent form and when speaking to them.
<b>Literacy</b>	Offer written and oral communication options.
<b>Comprehension</b>	Use simple words to explain CLM and how participants are being asked to engage in it. Avoid acronyms, abbreviations and jargon. Speak slowly and clearly.
<b>Age</b>	If a person is under 18 years of age, they cannot consent to participate in CLM without their parents or caregiver (a legal guardian) being present. For this reason, it is generally advisable to sample adults over the age of 18 years. If CLM is specifically aiming to sample adolescents and young people, you must obtain consent from the participant, as well as their parents or caregivers.

BARRIER TO INFORMED CONSENT	HOW CLM AND RELATED ADVOCACY CAN OVERCOME THE BARRIER
<b>Timing of the discussion</b>	Asking participants to answer questions before they have accessed health services may lead them to see CLM participation as a requirement for access to those services. It is advisable to ask for participants' engagement after they have received the services they came to the facility for. Reinforce that their participation is voluntary.
<b>Amount of time allotted</b>	Ensure adequate time for the discussion so the participant (and the data collector) do not feel rushed.
<b>Social desirability bias</b>	This refers to the tendency among research participants to choose responses they believe are more socially desirable or acceptable, rather than choosing responses that are reflective of their true thoughts or feelings. This means that a person may say they agree to participate in CLM when they really do not want to do so. Make sure that you clearly offer the acceptable option of not participating in CLM. It might be a good idea to repeat this option several times.

Once data is collected, **three interrelated concepts** affect protection of that data:



**PRIVACY** is both a legal and an ethical concept. The legal concept refers to legal protection that an individual has to control access to and use of personal information. Privacy provides the overall framework within which confidentiality and security are implemented. Privacy protections vary between jurisdictions and are defined by law and regulations.



**CONFIDENTIALITY** relates to a person's right to protect their data during storage, transfer and use to prevent unauthorized disclosure of that information. Confidentiality policies and procedures should include discussion of appropriate use and dissemination of health data, systematically considering the ethical and legal issues as defined by privacy laws and regulations.



**SECURITY** is a collection of technical approaches to address issues covering physical, electronic and procedural protection of the information that has been collected. Security discussions should include identifying potential threats to systems and data. These discussions should address protecting data from inadvertent or malicious and inappropriate disclosure system failure and user errors that make data unavailable.

**SOURCE:** UNAIDS (2019) *The Privacy, Confidentiality and Security Assessment Tool: User Manual*.  
 Online at [https://www.unaids.org/sites/default/files/media\\_asset/confidentiality\\_security\\_tool\\_user\\_manual\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/confidentiality_security_tool_user_manual_en.pdf)

## CHECKLIST FOR PROTECTING THE PRIVACY, CONFIDENTIALITY AND SECURITY OF PARTICIPANTS IN CLM

- ✓ **Ensure that you have participants' informed consent before asking any questions.**
- ✓ **Ask questions in a safe and quiet place, where you cannot be seen or heard by other people.**
- ✓ **Never record participants' names on data collection tools or in electronic databases.**
- ✓ **Have a written data security policy that defines how data are collected, stored and shared.**
- ✓ **Limit the number of people who have access to CLM data.**
- ✓ **CLM should be stored securely (for example, in a password-protected computer).**
- ✓ **Ensure secure data transfer through the use of secure internet (for example, <https://>).**
- ✓ **Manage permissions and access privileges to the data portal and transfer mechanisms.**
- ✓ **Put passwords on computers and documents where CLM data are stored digitally.**
- ✓ **For paper-based CLM, make sure that questionnaires are kept in a locked cabinet.**
- ✓ **Once the data is transferred to the portal, delete raw materials that were used to collect it.**

**FIGURE 2 A sample informed consent form for participants in CLM**

## INFORMED CONSENT FORM TO BE SIGNED BY ALL PARTICIPANTS

Hi. My name is **[DATA COLLECTOR'S NAME]**. I am part of a team that is implementing community-led monitoring interventions in **[LOCATION]**. I am going to start by explaining this project and making sure you are comfortable participating. Is it all right if I continue?

### DESCRIPTION OF THE PROJECT

- You are invited to participate in CLM implementation.
- CLM is a mechanism that systematically and routinely collects and analyses information from health facilities and the people who access services there.
- The purpose of the project is to analyse this information to identify gaps in access to and quality of services and care and to inform advocacy for improving them.
- You have been asked to participate because you have accessed services at **[FACILITY NAME]**.
- This study will include a sample of about [number] participants from **[NUMBER]** health facilities.

### WHAT WILL YOUR PARTICIPATION INVOLVE?

- If you decide to participate in this project, you will be asked to answer **[NUMBER]** questions. This part will take about **[ESTIMATED LENGTH]** minutes.
- You might also be asked to participate in a group discussion, where you will be asked to share more about your experience accessing services at this health facility. This part will take about [estimated length] minutes.
- You are free to ask any questions that you have before, during and after the interview.

### ARE THERE ANY RISKS TO ME?

- This project is anonymous. Neither your name nor any other identifying information will be recorded in the questionnaire or in the final report.
- Due to the nature of HIV and sexual and reproductive health, several questions are personal in nature and others include topics like sex and stigma and discrimination.
- If at any time you are uncomfortable with the content of the discussion, you may choose to skip a question or stop participating completely. Completion of all the questions is voluntary and you may stop or withdraw at any time.

### ARE THERE ANY BENEFITS TO ME?

- After completion of these questions, you will be given information about HIV and sexual and reproductive health and rights. This may benefit your own awareness and access to services.
- You will be given a transport allowance of **[AMOUNT]** for your participation in this project.
- Your participation will help improve access and quality to HIV prevention, services and treatment in **[COUNTRY NAME]**.

Please feel free to contact the community treatment observatory team leaders. If you have any questions about this process, the contact details of the team leader are:

- **[NAME] [PHONE NUMBER]**
- **[NAME] [PHONE NUMBER]**

**STATEMENT OF CONSENT:** I have read/heard and understood the above information and I have had all my questions answered by the interviewer. I agree to participate in the process voluntarily.

NAME OF THE PARTICIPANT \_\_\_\_\_

SIGNATURE OF THE PARTICIPANT \_\_\_\_\_

NAME OF THE INTERVIEWER \_\_\_\_\_

SIGNATURE OF THE INTERVIEWER \_\_\_\_\_

DATE OF THE INTERVIEW: \_\_\_\_\_

## Data use for advocacy: Visualization, advocacy, strategic communications and local feedback

For CLM to be effective, data must be analysed and used as evidence to influence change. Remember, the end goal of CLM is not the data collection; it is using the resulting evidence to improve policy and practice.

### Making the numbers speak: How to analyse, visualize and operationalize data for a difference

Before designing your advocacy plan, it is a good idea to analyse and visualize the data for CLM. This will help you to see gaps, issues and opportunities. The way you analyse this data can make a big difference, as shown by the following examples.

---

**The end goal of CLM is not the data collection; it is using the resulting evidence to improve policy and practice.**

---

#### EXAMPLE 1 The importance of trend analysis

**FIGURE 4.** CLM data on viral load suppression among people living with HIV at St. Mary's Teaching Hospital from October to December 2020



Figure 4 shows hypothetical CLM data on the viral suppression rate among people living with HIV at St. Mary's Teaching Hospital from October to December 2020. On the face of it, these look like good results. It seems that St. Mary's Teaching Hospital has achieved the 2020 Fast-Track target that "90% of all people adhering to antiretroviral therapy will have viral suppression".

**FIGURE 5.** CLM data on viral load suppression among people living with HIV at St. Mary's Teaching Hospital from October to December 2020



However, if the data are disaggregated (meaning broken up by population, such as among women and adolescents) over the three-month period, CLM data suddenly point to a serious issue with viral load suppression at St. Mary's. **In Figure 5, we can see that the average rate of viral load suppression is falling.** This could be caused by problems with retention in care and/or with the availability of WHO-recommended treatment regimens.



**DATA ANALYSIS TIP:** Instead of asking yourself, "Are these results good?", ask yourself, **"Are these results better than before?"**

## EXAMPLE 2 The importance of age and sex disaggregation

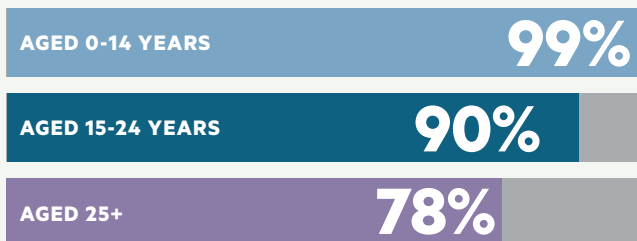
**FIGURE 6.** CLM data on the proportion of people living with HIV who received ART at St. Mary's Teaching Hospital from October to December 2020



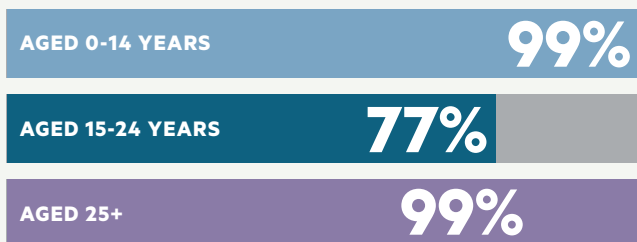
Figure 6 shows hypothetical CLM data on the proportion of people living with HIV who accessed sustained antiretroviral therapy at St. Mary's Teaching Hospital from October to December 2020. As with Example 1, this CLM data appear to show that the health facility is running an effective treatment programme. It seems that St. Mary's has achieved the 2020 Fast-Track target of 90% of people living with HIV being on ART.

**FIGURE 7.** CLM data on the proportion of people living with HIV who received ART at St. Mary's Teaching Hospital from October to December 2020

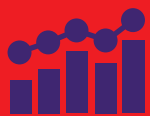
### MEN



### WOMEN



When CLM data in Figure 7 are disaggregated by age and sex, it becomes clear that not all people living with HIV in care at St. Mary's Teaching Hospital are accessing ART. **The figure highlights the CLM data: that young women aged 15-24 years and older men aged 25 years and over are being left behind.**



**DATA ANALYSIS TIP:** Instead of asking yourself, “Are these results good?”, ask yourself, **“Are these results good for everyone?”** Often, data on key populations are not disaggregated, obscuring the effectiveness and quality of services for gay men and other men who have sex with men, sex workers, transgender people and people who use drugs.





### EXAMPLE 3 The importance of benchmarking

**FIGURE 8.** CLM data on the % of people living with HIV at St. Mary's Teaching Hospital who received TB screening from October to December 2020

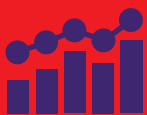
90%

Figure 8 shows hypothetical CLM data on the proportion of people living with HIV screened for TB at St. Mary's from October to December 2020. As with the previous two examples, the limited analysis makes it difficult to know if these results are good or not. It appears that St. Mary's is on track to achieve the 2020 End TB target of ensuring that 90% of people who have developed TB are notified and treated.

**FIGURE 9.** National data on the % of people living with HIV in the country of St. Maryland who received TB screening from October to December 2020

95%

If possible, it is always good to compare CLM data with information from another data source. This might include national-level data or data from another nearby health facility. **It is only by comparing the facility-level data in Figure 8 with national-level data in Figure 9 that it becomes apparent that St. Mary's is performing poorly.**



**DATA ANALYSIS TIP:** Instead of asking yourself, "Are these results good?," ask yourself, "**Are these results above or below average?**"

# Data-driven advocacy planning for CLM: A 10-step method

1

## Pick your advocacy priorities.

Looking at your data, identify the top advocacy priorities you want to push forward. There are two angles you can take when picking advocacy priorities, both of which may be useful and strategic depending on your context:

- **OPTION A: Focus on the biggest gaps.** For this option, you can ask yourself questions like, “Where are the biggest gaps between the way the world is and the way the world should be?” In other words, look at your data and identify the areas where things are most severely off track, where targets are most likely to be missed, or where populations are left furthest behind. These issues may be strategically selected as your top advocacy priorities.
- **OPTION B: Lean against an open door.** Another option is to ask yourself, “Where am I most likely to be successful and make a significant difference?” This might include looking at your data and picking issues where you can see there is a positive trend and progress is being made. By selecting this issue, your advocacy may be the catalyst to get an issue over the finish line, especially if there is already some forward momentum. This might include a policy issue that has been gaining traction in recent months. It also might include a target that is nearly – but not quite – achieved.

### EXAMPLE: Advocacy priorities for a CLM approach:

- Expand the availability of non-facility-based HIV testing options, including community-led and community-based HIV testing services.
- Intensify HIV communication and awareness campaigns to increase demand for HIV testing services.
- Include objectives that promote and protect the human rights of people living with HIV and members of key populations in costed HIV strategic plans.
- Improve communication along the supply chain to prevent ARV and other stock-outs.
- Enhance linkage to – and retention in – care and treatment, especially for members of key and vulnerable populations.
- Strengthen community systems and responses to support the roll out of differentiated service delivery (DSD).
- Increase funding to ensure the availability of a sufficient number of viral load testing machines and laboratory supplies for them.
- Enhance knowledge among people living with HIV and health care workers to increase demand for high-quality viral load testing services.
- Ensure effective treatment monitoring through acceptable turnaround times for viral load test results.

### We recommend selecting no more than five issues to ensure that your efforts remain focused.

This will help you avoid the “shopping list” critique, where activists are sometimes dismissed for having too many priorities that do not appear well thought through.

2

### Rank your priorities in order of importance.

This will help you plan your time and resources for your advocacy work. It will also help you be more credible at the negotiating table. To pick the top priorities, you might yourself, “Which issues should be attended to first?” or “Which ones are the most urgent?”

3

### Provide a rationale for your priorities.

Clearly explain why you have selected the advocacy priority. It is important to use evidence from CLM data to defend the advocacy priority. **For example:**

**ADVOCACY PRIORITY:** Ensure that treatment monitoring is effective by providing viral load test results promptly.

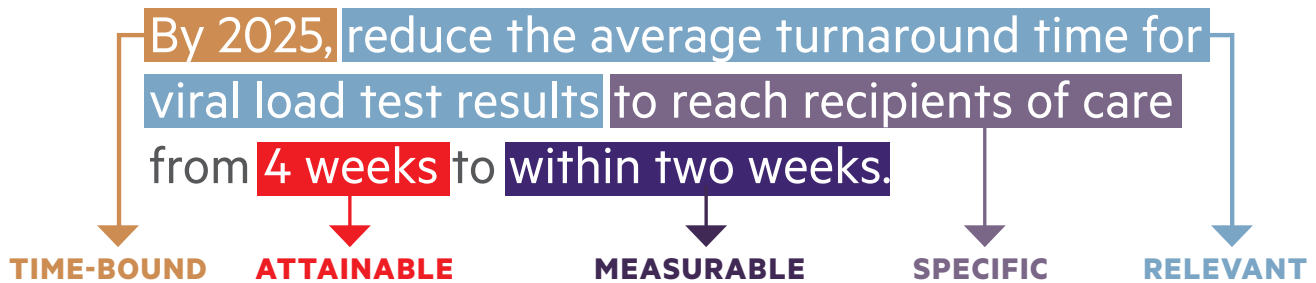
**RATIONALE:** Among 10,000 viral load tests performed at facilities undergoing CLM between January and June 2018, just 2,500 (25%) were returned to the recipient of care within two weeks. Our CLM data show that there is a connection between faster turnaround times and better treatment outcomes: in facilities where a larger proportion of viral load tests are returned within two weeks, viral suppression among people living with HIV on ART is higher (p <0.05).

4

### Set short-, medium- and long-term objectives

Advocacy priorities should be high-level problems that you want to fix. To make them more manageable, it is a good idea to break them down into short-term objectives (something you want to achieve in the next few months), medium-term objectives (something you want to achieve within the next year), and long-term objectives (something you want to achieve in the next few years). Try to make your advocacy objectives **SMART** (**S**pecific, **M**easurable, **A**ttainable, **R**elevant and **T**ime-bound).

**EXAMPLE: SMART advocacy objectives for a CLM approach**



**5****Establish your target audience(s).**

Map your target audiences for sharing and discussing CLM advocacy data. Your audience should be the people you want to hear your message and act on it. They should be people who are in a position of power to enact the change you want to see. We recommend considering a diverse range of sectors for your potential target audience, including government, civil society, the media, the private sector, donors, technical partners and academia. You can consider identifying a primary target audience, as well as a secondary target audience. For example, your primary target audience might be laboratories that you want to have batch and streamline samples so that facilities get their results more quickly. Your secondary target audience might be health care providers who should notify the client of their test result as soon as it is received from the laboratory.

**6****Identify friends and foes.**

For your message to be heard and acted upon, it is important to know who might be able to help you along the way, as well as who might potentially oppose you. Identifying your allies and your friends is very important. Friends can help amplify your voice, might support your advocacy with funding, or might already have the ear of your target audience. It is equally important to identify your foes: the people who might oppose you by standing in your way or discouraging you. Identifying these actors will help you avoid them or develop specific strategies to engage them effectively.

**7****Map entry points.**

Consider when and where you will be able to advance your advocacy agenda. Entry points might include a location, a date or both. For example, there might be a key meeting or conference coming up where you can present your data and push your advocacy priority. An upcoming launch of a report, where people will be focused on your issue, could create an opportunity for you to add your voice to the conversation. Entry points may be infrequent events (for example, global conferences) or more regular occurrences (for example, national technical working group meetings).

**8****Plan activities and expected results.**

This will include the practical aspects of what you will actually do to push your advocacy agenda. It might include developing advocacy briefs, preparing PowerPoint slides, submitting abstracts to conferences, making phone calls, requesting meetings with decision makers, and securing TV or radio spots. For each activity, try to consider the intended results. You can ask yourself, “What do I want to achieve from this action?”

9

### Consider available resources for implementing your advocacy plan.

This step includes thinking about the human, financial and time-based resources you might tap into to implement your advocacy plan. You might think about opportunities for funding from existing or potential donors and consider which CLM team members have the skillsets and time available to implement the advocacy activities.

10

### Determine measurements of success.

How will you know if your advocacy is successful? Setting measurement criteria for success is critical. You may be able to assess the effectiveness of your advocacy through ongoing CLM data collection. Or you might need to do a separate assessment or evaluation.

## ACTIVITY: ELEVATOR PITCH

Practice your “elevator pitch” to hone your advocacy skills



### Pretend you have just entered an elevator. Inside, you spot a top government official who is the target audience for your advocacy priority.

You are both riding up to the 10th floor of the building, a journey that will take you approximately one minute. In this time, you need to explain your advocacy agenda to this person and convince them to act. Stand next to a colleague or friend and practice your elevator pitch. Set a timer or a stopwatch for one minute. See if you can explain things to them in a short space of time and see if they are convinced or not by your advocacy.

**Good luck!**

### TIPS FOR EFFECTIVE CLM IMPLEMENTATION:

- Always use examples from your data to substantiate your claims.
- Convince your audience of the rigour with which you collected and analysed your data. This may include underscoring your sample size or noting collaborations with academic institutions





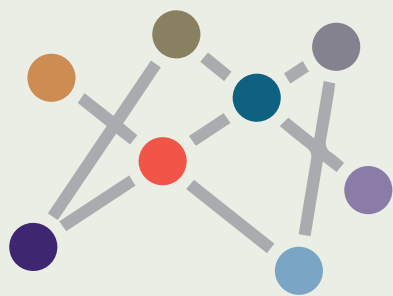
# RESOURCING AND FINANCING OF CLM

**TABLE 6 Costing categories for CLM**

CLM COMPONENT	DETAILS	RECOMMENDED COSTING CATEGORIES (Resource considerations)
<p><b>Education</b></p>	<p><b>Conduct interactive treatment education and capacity building with community members</b> to provide them with relevant knowledge of HIV, COVID-19 and TB, as well as human rights.</p> <p><b>Communities need to understand what they are monitoring:</b> what to collect, why to collect it, and how it will be used.</p>	<ul style="list-style-type: none"> <li>→ <b>Situational analysis:</b> Identify any existing CLM efforts and/or identify known issues to build upon in inception meetings: national level, district level, community level (transport, conference package or hall hire, facilitation, printed materials, audio-visuals, refreshments)</li> <li>→ <b>Training curriculum</b> (write and publish training toolkit, hire meeting facilitator or trainer, provide internet access)               <ul style="list-style-type: none"> <li>• Supplies (stationery and pens, flip charts)</li> <li>• PPE (hand sanitizer, masks)</li> </ul> </li> <li>→ <b>Staffing costs:</b> Focal point, data supervisors, M&amp;E lead</li> <li>→ <b>Core support for lead CLM organization</b> (overheads, administrative fees, part-time finance and programmatic support)</li> </ul>
<p><b>Evidence</b></p>	<p><b>Define scope of CLM implementation:</b> Identify priority issues and develop indicators, including disease-specific and COVID-19-sensitive indicators. (For example: Will your activities focus on prevention, diagnosis, treatment, care or support or community systems? Which of the “five As” would be your focus? What is the problem you want to address?)</p> <p><b>Data collection and management:</b> Develop data collection tools to capture information and disaggregate this data within the framework of your indicators. Pilot data collection tools and gather baseline data. The data management process should include data verification, quality assurance procedures and routine review of data.</p> <p><b>Data analysis:</b> Conduct a routine review of data to analyse trends, compare pre-COVID data with current monthly trends where available, identify bottlenecks and identify successes from the review of data and analysis.</p>	<ul style="list-style-type: none"> <li>→ <b>Staffing costs:</b> Data collectors (two staff per X site, data collection recurs on a monthly or quarterly basis); data team including data supervisor, M&amp;E officer and focal point lead person</li> <li>→ <b>Equipment:</b> Paper, tools, tablets for data collectors, transportation for data collectors, internet/data bundle for data collectors, raincoats, laptops, bags, PPE, etc.</li> <li>→ <b>Data management costs:</b> Support for organizing and systematizing the monthly reporting process. Support for analyzing incoming data, including coding qualitative data</li> <li>→ <b>Data platform:</b> Hosting, access, maintenance, etc.</li> <li>→ <b>Fees for securing ethical approvals</b> and implementing recommended privacy and safety protocols</li> <li>→ <b>Baseline assessment</b></li> <li>→ <b>Training:</b> Data team, data collectors</li> <li>→ <b>Monthly focus group meetings for qualitative data collection,</b> voice recorders, monthly supervisory visits</li> <li>→ <b>Core support</b> for the organization overseeing CLM</li> </ul>



CLM COMPONENT	DETAILS	RECOMMENDED COSTING CATEGORIES (Resource considerations)
<p><b>Engagement</b></p>	<p>Convene regular monthly or quarterly meetings through a CCG or other multistakeholder engagement process for co-creating solutions, such as a Country Coordinating Mechanism (CCM) or COVID-19 response task team. Include representatives from national networks of people living with HIV, TB survivor groups, malaria initiatives, key population groups, health care facilities, recipients of care, public health and HIV experts, programme managers, policy makers and academic partners.</p>	<ul style="list-style-type: none"> <li>→ <b>Support for CCG convenings</b> (transport, meeting costs, facilitation, printed materials, audio-visuals): biannually at national level; quarterly at the district level</li> <li>→ <b>Writing and disseminating quarterly reports</b></li> <li>→ <b>Core support</b> for CLM host organization</li> </ul>
<p><b>Advocacy</b></p>	<p>When data collection reveals gaps in access to and quality of services, the CCG meets with relevant decision and/or policy makers to co-create solutions for them (stock-outs, human rights issues, and other problems) and to hold decision makers to account, as needed. Push for implementation of co-created solutions as needed if progress is lacking.</p>	<ul style="list-style-type: none"> <li>→ <b>Support</b> for policy analysis and design and development of advocacy campaigns</li> <li>→ <b>Meet with policy makers</b> about advocacy issues at national, district and community levels (transport, meeting costs, printed materials) at least biannually, ideally quarterly</li> </ul>



# ANNEXES





# ANNEX A

## UNAIDS, Global Fund and PEPFAR definitions of CLM

ORGANIZATION	DEFINITIONS
<p><b>UNAIDS</b> <i>Community-led monitoring (CLM)</i></p>	<p><b>WHAT:</b> A accountability mechanism for HIV responses at different levels, led and implemented by local community-led organizations of people living with HIV, networks of key populations, other affected groups or other community entities. CLM uses a structured platform and rigorously trained peer monitors to systematically and routinely collect and analyse qualitative and quantitative data on HIV service delivery—including data from people in community settings who might not be accessing health care—and to establish rapid feedback loops with programme managers and health decision makers. CLM data builds evidence on what works well, what is not working and what needs to be improved, with suggestions for targeted action to improve outcomes.</p> <p><b>WHO:</b> Local community-led organizations of people living with HIV, key population groups, other affected groups and other community entities.</p> <p><b>WHY:</b> The CLM model and interventions serve as a watchdog for the national HIV response and allow communities, health facilities and governments to rapidly identify and respond to barriers to HIV services.</p>
<p><b>The Global Fund to Fight AIDS, Tuberculosis and Malaria</b> <i>Community-based monitoring (CBM)</i></p>	<p><b>WHAT:</b> A mechanism by which service users gather, analyse and use information on an ongoing basis to assess and improve the effectiveness, quality, accessibility and impact of health programmes and services they receive. Communities decide what to monitor and act upon the data through evidence-based advocacy. CBM can monitor HIV, TB and malaria services, as well as the availability of essential drugs and human rights violations.</p> <p><b>WHO:</b> Service users and local communities.</p> <p><b>WHY:</b> Improve access to, and quality and impact of, services and hold service providers and decision makers to account.<sup>i</sup></p>

(1) [https://www.theglobalfund.org/media/9622/core\\_css\\_overview\\_en.pdf?u=637319006203930000](https://www.theglobalfund.org/media/9622/core_css_overview_en.pdf?u=637319006203930000)



ORGANIZATION	DEFINITIONS
<p><b>US President’s Emergency Plan for AIDS Relief (PEPFAR)</b> <i>Community-led monitoring</i></p>	<p><b>WHAT:</b> An approach initiated by communities to routinely and systematically collect quantitative and qualitative data on HIV services from recipients of those services.</p> <p><b>WHO:</b> Implemented by community-based and civil society groups, networks of people living with HIV and key populations or other affected and/or community entities.</p> <p><b>WHY:</b> Aims to translate the data insights into action and change. It is important because it places community needs and voices at the heart of the HIV response.<sup>ii</sup></p>

## Community data, defined and various examples

Several models of community monitoring have been implemented globally to match differing local contexts, infrastructure and capacities.

**Health facility committees:** Health care providers and community representatives come together in health facility committees, track and review grievances raised by health care beneficiaries, and then regularly provide feedback on how these have been addressed.

**Citizen report cards:** These track the quality of health services according to metrics that communities have identified and prioritized. Progress on these metrics can be measured against a national standard or the performance of other local health facilities. To address these issues, assessments are best reviewed in meetings between health care providers and communities.

(ii) US Department of State <https://www.state.gov/community-led-monitoring/#:~:text=Why%20does%20PEPFAR%20support%20Community,the%20community%20and%20facility%20level>



**Community scorecards:** These rely on indicators that have been developed collaboratively by community representatives and health care providers. These indicators are used to track the performance and quality of health systems and translated into an action plan that is jointly assessed by communities and health care providers.

**Health advocates:** They have been the channel for addressing health care beneficiary grievances in some settings. In addition to educating communities on local health policy standards and their rights, health advocates also collect grievances and track their resolution. Health advocates work with health care providers to craft solutions for the problems they have identified and devise a timeline for action.

**Community observatories:** Community observatories regularly and systematically collect quantitative data (from health facility records) and qualitative data (from recipients of care) on the quality of services along the HIV prevention, testing, care and treatment cascade. Trained community representatives gather data, track trends against a baseline, and advocate for changes as needed.

**Community health observatories:** Similarly, community health observatories rely on health monitors, community representatives or community health workers, who report deviations and/or dysfunctionality in service delivery at health facilities to observatory facilitators, using phone applications or at in-person meetings.



## ANNEX B

# Menu of quantitative and qualitative indicators for HIV-focused CLM and related advocacy

**TABLE 8** Examples of quantitative indicators that can be collected through CLM

AREA	INDICATOR	DISAGGREGATION
Prevention and testing	Number of HIV tests performed	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number of positive HIV test results	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Positive test results as a proportion of the total number of tests performed (HIV positivity)	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Has there been a stock-out of HIV test kits in the past month (yes/no)	Type of test (rapid, blood, self)
	If a stock-out of test kits has occurred, how many days did it last before it was resolved?	n/a
	Number of people initiated onto PrEP	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number or % of people retained on PrEP one month after initiation	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number of people initiated onto post-exposure prophylaxis (PEP)	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number or % of people who complete the full 28-day course of PEP	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)

AREA	INDICATOR	DISAGGREGATION
<b>Care and treatment</b>	Number or % of people living with HIV who received a baseline CD4 count test before initiating ART	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number or % of people living with HIV presenting with advanced disease (CD4 count <200 cells/mm <sup>3</sup> )	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number or % of people living with HIV who have a positive result and are newly initiating ART	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number of people living with HIV receiving ART	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number or % of people living with HIV known to be on ART 12 months after initiating it	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Has there been a stock-out of ARVs in the past month (yes/no)	Type of ARV (name of medicine); regimen (1st line, 2nd line, 3rd line, paediatric)
	If a stock-out of ARVs has occurred, how many days did it last before it was resolved?	n/a
	Number or % of people living with HIV screened for TB	Age (0-14/15+); sex (M/F/T); population (general population, pregnant women, people who inject drugs, transgender people, mineworkers/ex-mineworkers, health care workers, migrant populations, prisoners)
	Number or % of eligible people living with HIV initiated on TB preventive therapy	Age (0-14/15+); Sex (M/F); Population (Gen pop, pregnant women, PWID, mineworkers/ex-mineworkers; health care workers; migrant populations; prisoners)
<b>Adherence and viral suppression</b>	Number or % of people living with HIV enrolled in DSD	Type of DSD model (fast-track, community-based ART refill groups, facility-based ART refill groups, multi-month dispensing, teen clubs, family-centred, etc.)
	Number of viral load tests performed	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number or % of people living with HIV who have received a viral load test in the past year	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Number or % of people living with HIV who received their viral load test results within two weeks of taking the test	Within 2 weeks; within one month; more than one month

AREA	INDICATOR	DISAGGREGATION
<b>Adherence and viral suppression</b>	Number or % of people living with HIV on ART who have achieved viral suppression	Age (<25/25+); sex (M/F/T); population (general population, men who have sex with men, sex workers, people who inject drugs, transgender people, prisoners)
	Has there been a stock-out of viral load testing supplies in the past month (yes/no)	Type of stock-out (reagents, chemicals, consumables, durables, other)
	If a stock-out of viral load testing supplies has occurred, how many days did it last before it was resolved?	Marker for care retention and quality of care

**TABLE 9** Examples of *qualitative* indicators that can be collected through CLM

TARGET AUDIENCE	QUESTION	FURTHER PROMPTS IF NEEDED
<b>Health care workers</b>	Tell me a bit about yourself. What is your role at this health care facility? How long have you been doing this work?	
	What are the reasons for stock-outs of HIV testing supplies?	Do communication issues along the supply chain play a role? Does incorrect forecasting and quantification play a role? Do issues with the central medical stores play a role?
	What are the reasons for stock-outs of ARVs?	Does the non-delivery of orders play a role? Does poor planning play a role?
	What are the reasons for stock-outs of viral load laboratory supplies?	Does reliance on donors play a role? Does non-payment play a role?
	What are the reasons for stock-outs in other facilities that you have heard about? (You can keep this anonymous.)	
	What are some of the other challenges you face in your health facility in terms of HIV prevention, treatment and care?	
	What would help you do your job better?	Would better pay help you provide better care? Would better supervision help you provide better care? Would better training help you provide better care? Would better job aides help you provide better care? Would shorter working hours help you provide better care? Would better appreciation by your boss help you provide better care?
	What are some of the successes of your facility in terms of HIV prevention, treatment and care?	Are there good information-sharing networks? Are there convenient treatment refill options (e.g., multi-month dispensing)? Are you partnering with recipient of care advocacy groups?

TARGET AUDIENCE	QUESTION	FURTHER PROMPTS IF NEEDED
<b>Recipients of care</b>	What are the reasons for people not receiving an HIV test?	<ul style="list-style-type: none"> <li>Does the distance to the HIV testing centre play a role?</li> <li>Do long waiting times at the health facility play a role?</li> <li>Do user fees or other out-of-pocket expenditures play a role?</li> <li>Does fear of discovering one's status play a role?</li> <li>Do stigma and discrimination play a role?</li> <li>Do health care workers' attitudes/friendliness play a role?</li> <li>Does lack of privacy and confidentiality play a role?</li> </ul>
	What are the reasons for people not receiving a CD4 test?	<ul style="list-style-type: none"> <li>Does knowledge of the importance of CD4 testing among people living with HIV play a role?</li> <li>Do long waiting times at the health facility play a role?</li> <li>Do user fees or other out-of-pocket expenditures play a role?</li> <li>Does the availability of working CD4 machines play a role?</li> <li>Do delays in returning the results to the recipient of care play a role?</li> <li>Do human resource challenges play a role?</li> <li>Do stock-outs of cartridges and reagents play a role?</li> </ul>
	What are the reasons for people not receiving ART?	<ul style="list-style-type: none"> <li>Does the distance to the ART centre play a role?</li> <li>Do long waiting times at the health facility play a role?</li> <li>Does payment or out-of-pocket expenditure play a role?</li> <li>Do side-effects play a role?</li> <li>Do stigma and discrimination play a role?</li> <li>Do ARV stock-outs play a role?</li> <li>Do inconvenient or limited refill options play a role?</li> <li>Do health care workers' attitudes/friendliness play a role?</li> <li>Does lack of privacy and confidentiality play a role?</li> </ul>
	What are the reasons for people not receiving a viral load test?	<ul style="list-style-type: none"> <li>Does the knowledge that people living with HIV have of viral load testing guidelines play a role?</li> <li>Do long waiting times at the health facility play a role?</li> <li>Does the availability of working viral load testing machines play a role?</li> <li>Do delays in returning results to recipients of care play a role?</li> <li>Do human resource challenges play a role?</li> <li>Do stock-outs of lab supplies play a role?</li> </ul>
	On a scale of 1 to 5 (5 being the best), how would you rate the overall quality of service at your health facility?	How would you describe the ideal visit to a health facility?
	Were you treated with respect by your health care worker today?	



# ANNEX C

## Community treatment observatory case studies

### CASE STUDY #1

### Improving access to viral load monitoring through the Regional Community Treatment Observatory in West Africa

---

**Building on previous work monitoring ARV stock-outs in the region, the RCTO-WA aimed to increase HIV treatment access in 11 West African countries.**

---

In February 2017, with support from the Global Fund, ITPC established the Regional Community Treatment Observatory in West Africa (RCTO-WA), which united organizations that were performing CLM. The RCTO-WA's purpose was to increase accountability for achieving the UNAIDS 90-90-90 targets. At the time, just 48% of people living with HIV in the region were aware of their status; 40% of them were accessing ART; and 29% of this group were virally suppressed. Progress towards universal treatment access was stymied by a range of diverse challenges, including drug stock-outs, weak health systems, human rights barriers and low quality of care.

Building on previous work monitoring ARV stock-outs in the region, the RCTO-WA aimed 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 in all focus countries.
2. Creating a regional treatment observatory
3. Building capacity among members of the 11 national networks of people living with HIV to do treatment monitoring

The project was housed under ITPC's Watch What Matters campaign, and it followed our community monitoring model.

A series of three technical planning workshops were held between December 2016 and February 2017 to train implementation teams from each country. These workshops focused specifically on work planning and capacity building for M&E, data collection, database use, financial management and governance. The training of local data collectors followed.

Based on specific criteria (such as population size and location), 103 health facilities were selected as designated data collection sites. ITPC signed an MoU with each facility. Of these, 43 were large district-level



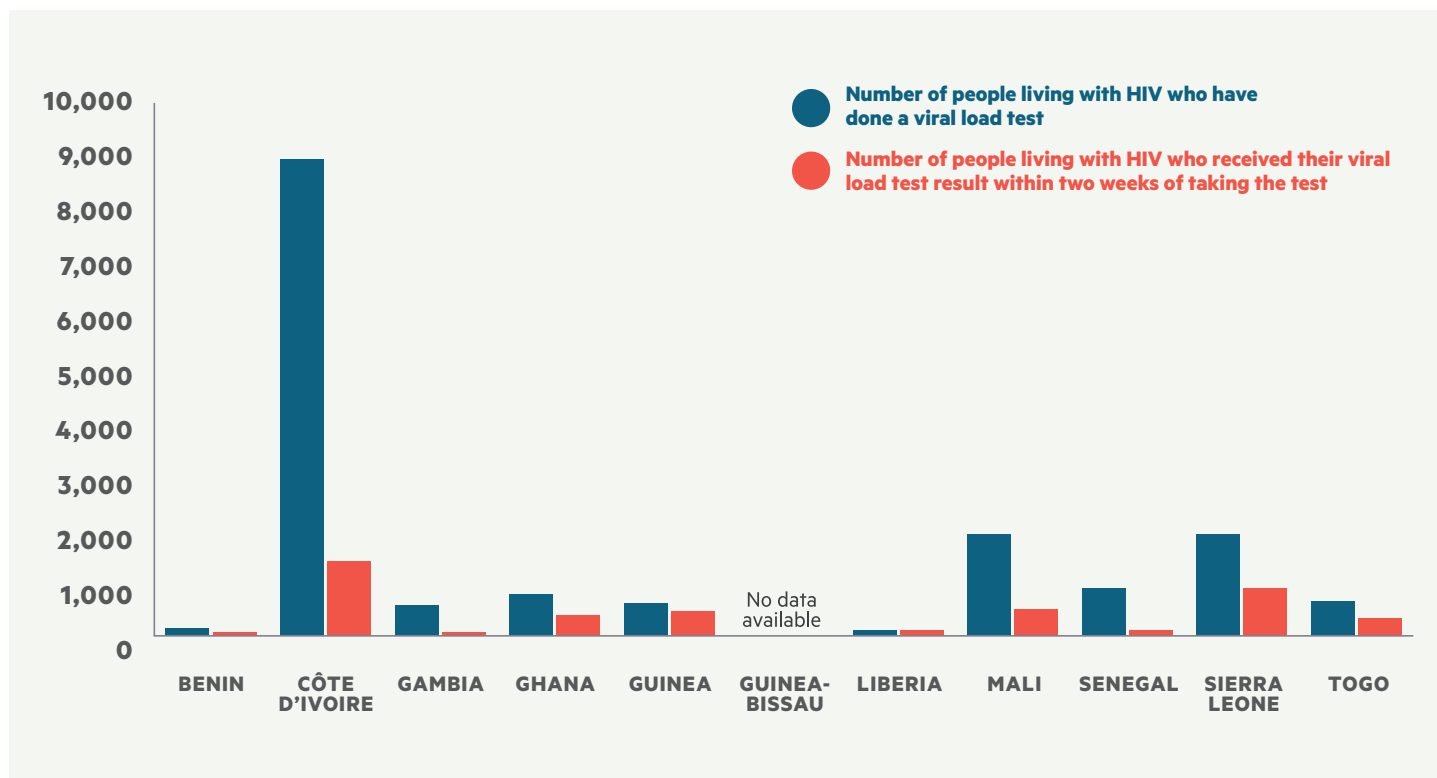
or regional hospitals, 28 were mid-level health centres, 19 were non-governmental organizations, nine were lower-level clinics and four were community-level health centres. From January 2018 to June 2019, the treatment observatory completed 1,781 monthly monitoring reports, 1,501 interviews and 143 focus group discussions. The data was analysed using a version of the “five As” (availability, accessibility, acceptability, affordability and appropriateness) conceptual framework to assess gaps and opportunities for improvement along the HIV treatment cascade. Feedback was provided to recipients of care, health centre staff and government decision makers through real-time alerts, quarterly reports and multistakeholder dialogues.

The initial findings of the RCTO-WA painted a clear and specific picture of the experiences among communities in West Africa, with particularly acute gaps in viral load monitoring. Just 20% of people living with HIV who were receiving ART had a viral load test during the previous six months. Only a quarter of viral test results were returned within two weeks, and the average

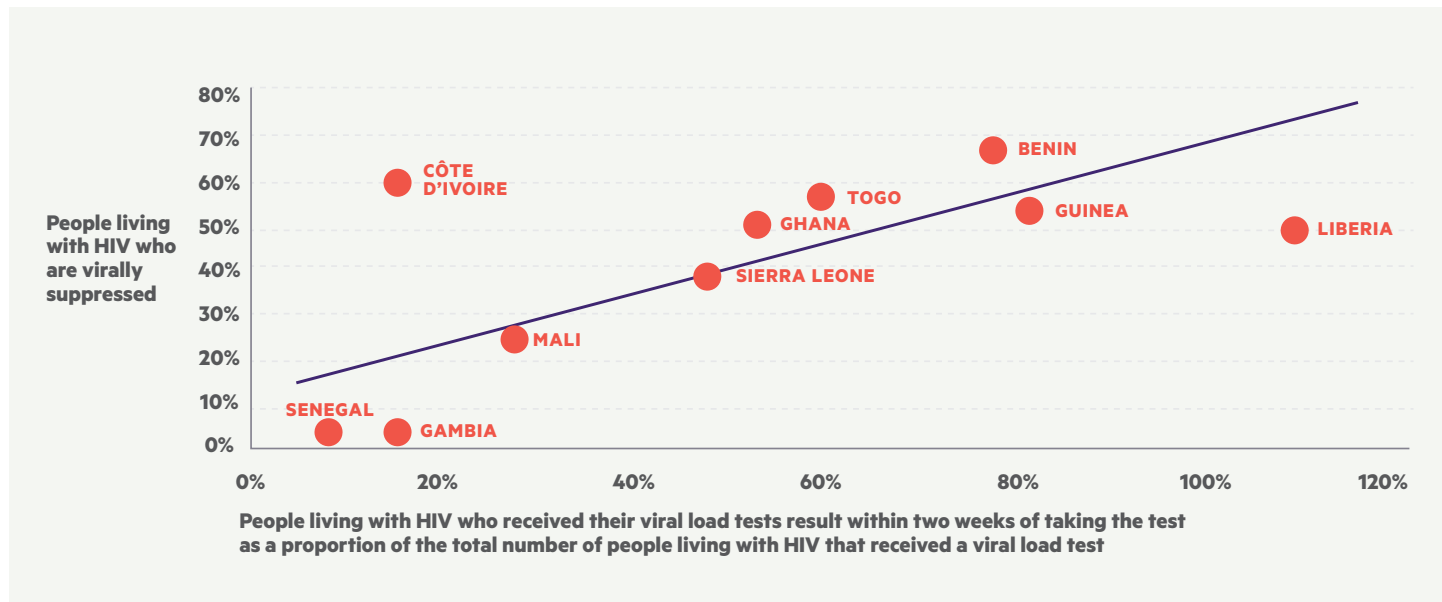
turnaround time for viral load test results was 4.5 months. Nearly one in 10 people cited the delay in the return of results as the reason for not accessing viral load testing services. Of those who received a viral load test, less than half (48%) were virally suppressed. RCTO-WA data also show a relationship between receiving timely viral load test results and the prevalence of viral load suppression.

It was clear that that the capacity and the critical need for viral load testing were not being met – and even where it was, results often failed to reach recipients of care, rendering the test meaningless to people living with HIV. The RCTO-WA data showed that routine viral load testing, as recommended by WHO, was not happening, and that test results were not reaching recipients of care. Essential information was not being used to help people living with HIV achieve and maintain viral suppression via receipt of an undetectable result or through adherence counselling and/or switching to a new regimen.

**FIGURE 10 Total number of people living with HIV who received a viral load test versus the number who received their viral load test result within two weeks (JANUARY-JUNE 2018)**



**FIGURE 11 Relationship between receiving timely viral load test results and prevalence of viral load suppression at RCTO-WA facilities (JANUARY-JUNE 2018)**



Armed with data that clearly pointed to a problem with routine viral load monitoring, the national-level community treatment observatories (CTOs) began to set and implement data-driven advocacy agendas, with guidance from their community consultative groups

(CCGs). A regional-level advocacy agenda was set during a Regional Advisory Board meeting in October 2018. For the third 90, three advocacy priorities were set, with seven key messages.

**FIGURE 12 The RCTO’s three advocacy priorities and seven key messages**

By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression	
<p><b>Increase funding to ensure the availability of adequate viral load testing machines and laboratory supplies</b></p>	<ul style="list-style-type: none"> <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>
<p><b>Enhance knowledge among people living with HIV and healthcare workers to increase demand for high-quality viral load testing services</b></p>	<ul style="list-style-type: none"> <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 centres must train their staff on viral load monitoring and provide supportive supervision to ensure that providers are conducting viral load testing at the right time.</li> </ul>
<p><b>Ensure effective treatment monitoring through acceptable turnaround times for viral load test results</b></p>	<ul style="list-style-type: none"> <li>→ The West African Health Organization (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>

CTO data was used to influence actions by a diverse set of decision makers to improve a range of HIV services. Important CTO success stories began to emerge.

## CTO SUCCESS STORIES



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 tests and CD4 cell counts. The CTO data on reagent stock 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.



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, for each patient.

As a result of CTO data collection and data-driven advocacy, there were key improvements in viral load

monitoring at RCTO-monitored facilities during the project.

**FIGURE 13** Key improvements at RCTO-monitored sites



## LESSONS LEARNED

### ✓ **Strong leadership is critical.**

The more successful observatories had strong leadership within the national network and high-level political buy-in. In Benin, the Office of the Presidency chaired the CCG. Initiatives must invest in strengthening the host organization, as well as feedback mechanisms (like the CCG), for the CTO to be successful.

### ✓ **The model must be embedded in the national response.**

Working closely with governments and other key national stakeholders was vital. Rather than finger-pointing, the treatment observatories created a culture of collective problem solving among health care workers, decision makers and recipients of care. Governments came to see the networks of people living with HIV as an asset and ally in the response.

### ✓ **Moving from ad-hoc alerts to systematic monitoring is key.**

This enabled the observatories to be proactive instead of reactive. By monitoring services along the entire cascade, other issues, such as stigma and discrimination as a barrier to access and gender-related health inequities, were unearthed.

### ✓ **Different observatories function at different levels.**

The differences in geographic coverage and the varying capacities of the national networks presented challenges. ITPC developed an accreditation tool, classifying the observatories into tiers.

### ✓ **Data-driven advocacy works.**

Results and analysis from the Côte d'Ivoire observatory caught the eye of Ambassador Deborah Birx, who was the United States Global AIDS Coordinator. This observatory was funded by PEPFAR in COP 19 and successfully advocated for the removal of user fees in the country.

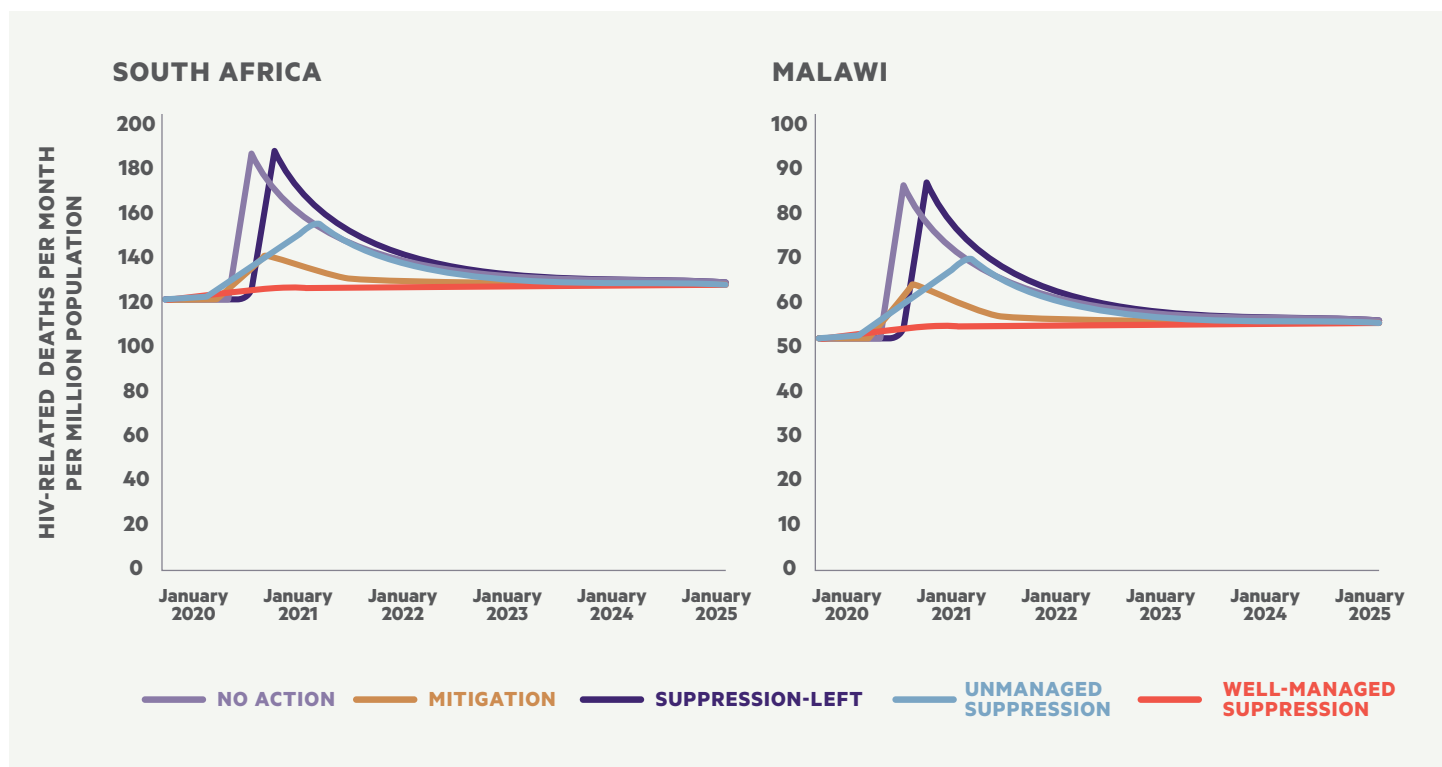
# Adapting CLM in South Africa and Malawi for COVID-19 realities

The greatest impact on HIV is estimated to be from ART interruptions, which may occur during a period of high or extremely high health system demand.

The COVID-19 pandemic is a historic global challenge. Many of the health and development gains of the past two decades – realized through pointed advocacy

and impassioned commitment to strengthening public health and human rights – are threatened by the impacts of this new disease on the health and livelihoods of billions. In high-burden settings, the COVID-19 pandemic may increase HIV- and TB-related deaths over five years by up to 10% and 20%, respectively (Figure 14).<sup>4</sup> The greatest impact on HIV is estimated to be from ART interruptions, which may occur during a period of high or extremely high health system demand. The greatest impact on TB is estimated to be from reductions in timely diagnosis and treatment of new cases, which may result from a long period of interventions to suppress COVID-19 transmission.

**FIGURE 14**  
Total deaths per million due to HIV under each COVID-19 epidemic scenario



( 4 ) Hogan, A. B., Jewell, B. L., Sherrard-Smith, E., Vesga, J. F., Watson, O. J., Whittaker, C., ... & Baguelin, M. (2020). Potential impact of the COVID-19 pandemic on HIV, tuberculosis, and malaria in low-income and middle-income countries: a modelling study. *The Lancet Global Health*, 8(9), e1132-e1141. Online at [https://www.thelancet.com/journals/langlo/article/PIIS2214-109X\(20\)30288-6/fulltext](https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(20)30288-6/fulltext)

In September 2020, with support from the Gates Foundation, ITPC began establishing specialized, COVID-19-sensitive CTOs in South Africa and Malawi. The goals were to: strengthen community-based responses to COVID-19 among people living with HIV and TB; improve public health outcomes in this time of crisis; and, ambitiously, to strengthen and empower public health activists to confront and manage the new pandemic.

A policy and data mapping exercise was performed to adapt standard CTO indicators to the new reality of COVID-19. This was done to ensure that the indicators tracked by the CTOs were relevant to national HIV and TB responses in the context of COVID-19. For example, this exercise revealed that Malawi's COVID-19

*Guidance for HIV Services* states that facilities are to document all recipients of care with any of four symptoms as “TB suspected” in the ART patient record to provide valuable routine data for COVID-19 surveillance. South Africa is prioritizing the rapid scale-up of community pick-up points for ART (such as post offices, grocery stores, churches and community halls) to decongest health facilities during COVID-19. More than 400 new pick-up points were registered between January and June 2020, a 20% increase from December 2019. CTO indicators were developed with these priorities in mind.

Experts estimated that the impact of COVID-19 on excess HIV-related deaths could be mitigated by maintaining ART supply for current recipients of

**TABLE 10 Example of COVID-sensitive CLM indicators**

INDICATOR	WHY IT IS RELEVANT IN THE CONTEXT OF COVID-19?
<b>QUANTITATIVE</b>	
Number of people living with HIV receiving multi-month ART dispensing	Countries are rapidly scaling up multi-month dispensing to decongest health facilities during COVID-19. Yet, evidence from UNAIDS suggests that the supply of medicines dispensed does not always match the policy, often due to stock unpredictability, which has been exacerbated by COVID-19.
Number of TB tests conducted using rapid molecular platforms	GeneXpert machines are being repurposed to test for COVID-19. As a result, rapid molecular TB testing rates have reportedly plummeted in many countries. In South Africa, for example, using these machines for COVID-19 testing resulted in a 48% decline in GeneXpert TB testing, which led to a 33% decline in the number of people diagnosed with TB and a significant decrease in TB case notifications.
Number of people living with HIV on ART who are lost to follow up	PEPFAR data show a 1.5% decline in treatment retention in South Africa – about 100,000 individuals lost from care – between 27 March and 5 June (during the Level 4-5 lockdown).
<b>QUALITATIVE</b>	
What are the challenges that people living with HIV face in adhering to ART now?	Food insecurity, mental health and the suspension of support groups for people living with HIV have all been reported since COVID-19 began. These issues are likely to affect the ability of people living with HIV to adhere to their medication.
How do legal restrictions on movement affect access to food, health care, shelter or other basic needs?	The Ugandan Medical Association reports that there have been delays in receiving travel permits during lockdown and that, in the interim, doctors who drive without them have been beaten, arrested and tortured.

(5) UNAIDS (2020) Rights in a Pandemic - Lockdowns, rights and lessons from HIV in the early response to COVID-19, pp. 31. Online at <https://www.unaids.org/en/resources/documents/2020/rights-in-a-pandemic>



care. As such, in Malawi, the government issued *COVID-19 Guidance for HIV Services*, which provided for dispensing a six-month supply of ARVs to people living with HIV on certain regimens. In South Africa, most provinces issued guidance that provided for dispensing a three-month ART supply. A UNAIDS study found that in Malawi, most people were receiving six months of ART whereas in South Africa, most people were receiving a two-month supply.<sup>5</sup> ITPC identified a critical need to monitor HIV responses in the context of COVID-19, including the rapid scale up of multi-month ART dispensing.

In the context of COVID-19, more than indicators had to be adapted. COVID-19 prevention measures have led most people to work remotely, and academic institutions have implemented e-learning. During social distancing, isolation and quarantine, technology has taken the place of physical interactions, including how people seek and access services. COVID-19 has and will continue to transform the way CTOs use technology for data collection, community education, advocacy and improving health systems and service delivery. ITPC conducted a technology mapping/situation analysis to explore how this could happen, which technology tools are currently being used, tools

that could be useful and feasible, and how technology could facilitate a cost-effective approach to multiscale, multisite real-time community-led data collection, use and integration with routine facility and national data systems.

Contingency plans for training and data collection had to be put in place. ITPC planned a series of virtual capacity buildings/trainings with the in-country project teams to ensure that they had sufficient knowledge of HIV, TB and COVID-19, including guidelines for prevention, testing, care, treatment and service delivery, M&E, data collection and management methods. These virtual trainings, which would ordinarily be done in-person, enabled trainees to understand what should be monitored, identify gaps in treatment access and challenges in their respective environments, and collect evidence for advocacy to improve health outcomes among recipients of care.

Next, 30 high-burden health facilities were selected for monitoring (15 in each country). Protocols were developed for how data could be collected while observing social distancing regulations or even remotely, if necessary.

(5) UNAIDS (2020) Rights in a Pandemic - Lockdowns, rights and lessons from HIV in the early response to COVID-19, pp. 31. Online at <https://www.unaids.org/en/resources/documents/2020/rights-in-a-pandemic>



### Political engagement and mobilization of national stakeholders

Implementing CLM interventions was a key recommendation for community systems strengthening in Namibia's mid-term review of the HIV National Strategic Framework 2017-2022.

**July 2020:** Virtual consultations were held with CSOs and the National Monitoring and Evaluation Technical Advisory Committee about collaboration with UNAIDS and the United States Government to support CLM in Namibia.

#### September 2020 to November 2020:

A transparent process was established for selecting CSOs to implement CLM, including a panel of representatives from CSOs, the MoH, UNAIDS and the US Government. Contracts were made with three independent organizations (Society for Family Health, Positive Vibes, Catholic AIDS Action).

### ITPC support to UNAIDS/ Namibia

ITPC helped build consensus around the definition, aim and scope of CLM. A national strategy for CLM was adopted, with CSO and community leadership and ownership, and a government partnership was established for integration with its multisectoral information system. A CLM protocol was developed,

with support from the US Centers for Disease Control and Prevention (CDC), USAID and PEPFAR, reviewed by ITPC, and cleared by Namibia's Ethical Committee. CLM tools were developed and CSOs were trained on their use

### Support from the Global Fund and the US Government

The CDC, PEPFAR and USAID provided guidance throughout the process, from developing the CLM proposal to securing ethical clearance.

The Global Fund's Program Management Unit supported national consultations and is actively supporting the CSO/MoH support team by creating an enabling environment for, and providing oversight of, CLM.

### Challenges

COVID-19 caused disruptions and delays; these challenges were discussed during monthly meetings with CDC, PEPFAR and UNAIDS.

A PEPFAR-developed monitoring map was used to determine the best ways to continue delivering HIV prevention and treatment services.

### Next steps

Data collection was rolled out in April 2021 and is still taking place. Data validation and analysis,

report writing, dissemination and advocacy will be subsequently implemented.

## LESSONS LEARNED

### ✓ **The CLM approach in Namibia was institutionalized at the national level.**

Civil society partners, the MoH and development partners (UNAIDS UCO, Global Fund, PEPFAR and CDC) convened to develop a National CLM Strategy, which was aligned to Namibia's National Strategic Framework. Although the CLM strategy design process included multisectoral partners and stakeholders, ownership of the CLM strategy remained community-led. Three grassroots implementing partners were selected to lead the programme. This was a unique and good practice example of a nationalized and endorsed CLM approach.

### ✓ **The technical assistance support for Namibia was equally comprehensive, with support provided to:**

- Conduct a situational analysis and mapping of Namibia's HIV response
- Host a CLM orientation webinar to build capacity and awareness of CLM methodology
- Facilitate a series of community and stakeholder consultative sessions to identify and unpack CLM priorities
- Develop a national CLM strategy and present the framework to the National Aids Council (NAC), MoH (M&E unit) and other technical working group meetings on strategic initiatives and M&E
- Design and develop Namibia's CLM implementation plan, inclusive of indicators framework, data management and tools, data collection processes, etc.
- Provide training to implementing partners, Global Fund programme implementation unit and MoH on CLM methodology and data collection/M&E, HIV, TB & COVID-19 treatment education training – for data collectors, programme officers and M&E personnel
- Review of ethical clearance protocols
- Provide technical support for pilot data collection and refining data collection tools and the CLM process

### ✓ **UNAIDS UCO and the three implementing partners are set to conduct data collection as of 1 April 2021 with full endorsement by the MoH.**



## ANNEX D

# CLM and community and institutional systems strengthening

---

**CLM and related advocacy are designed to improve quality of and access to HIV services, while strengthening community-based organizations and networks of people living with HIV.**

---

Community-based organizations often struggle to meet the evolving needs of people they serve, keep their staff trained, develop strong governance structures and sustainability plans and, at the same time, fulfil donor reporting requirements. CLM and related advocacy are designed to improve quality of and access to HIV services, while strengthening community-based organizations and networks of people living with HIV. The foundation of a sound CLM and related advocacy model is ensuring that the host organization has the requisite skills and systems in place to implement interventions, manage the team and oversee the financial management of any grants received.

CLM host organizations and/or CLM implementers are defined as community-led organizations representing affected and concerned populations, such as people living with HIV, key populations, women and young people. They are often a formal coalition of organizations with a written agreement covering ways of working together, mutual accountability and conflict resolution.

Host organizations become custodians and gatekeepers of community data, so the network skills and systems needed to implement CLM must be developed. Host

organizations benefit from CLM evaluations and ongoing assessments of their functionality and overall health, which identify areas for improvement. When communities lead CLM interventions and approaches, there is:

- **Ownership of the process.** Communities have a vested interest in the outcomes; data that have been collected do not “vanish” as they often have with traditional researchers. Community systems are also strengthened in the process: staff develops skills in data management, M&E and advocacy while organizations build and maintain their track records.
- **Appropriate and responsive interventions.** Solutions are closer to the issues; community-led interventions can generate more valuable and honest insights to address pressing needs.
- **Action- and accountability-focused results.** Data collection and analysis are for a purpose; they are directly linked to advocacy or other targeted action to improve quality and service delivery and hold those in power accountable.

Although not mandatory, an accreditation process helps build sustainable institutional systems for CLM and host organizations to ensure quality and attract and maintain donors. Once CLM has been embedded into the operations of the host organization, external reviewers can assess the host organization’s systems, policies and governance, and the effectiveness of CLM work can be rated across four areas (education, evidence, engagement and advocacy). Accreditation team reviewers develop recommendations based on the overall assessment and scoring across different areas to strengthen the host organization and/or CLM implementers.

## The accreditation tool outlines standards for assessing the host organization across six areas:

1

Existence of **good governance and accountability practices**, such as a board that meets regularly. Board members need to have the requisite skills for oversight and good governance and management, and defined roles and responsibilities (that is, terms of reference for the chair, treasurer, secretary). The board constitution and minutes from all board and staff meetings are available and the organization complies with national laws and regulations. The decision-making processes are clear and transparent.

2

**Existence of good policies that govern organizational operations.** Policies are in place (standardized procedures manual, templates for descriptions of governance structure and reports; organizational diagrams and job descriptions; financial and project reporting, policy, risk and fraud management). These are used to guide organizational operations. The organization has a child protection policy, and safety and security policies for beneficiaries are in place. The organization has strong capacity and systems for effective management and oversight.

3

**Leadership of the organization operates openly and transparently**, following its governance policies. The decision-making process is clear, governance policies have been shared with staff, and staff is informed of key decisions.

4

**Leadership and management structure**, with the roles and responsibilities of the organization's leadership defined. Terms of reference or job descriptions or a human resources manual are available and approved by the board.

5

**Adequate number of skilled staff** to implement its functions (such as programme, finance and M&E). Staff performance is continuously assessed, and refresher training to improve the capacity of staff is provided.

6

**Strategic and resource mobilization plans** outline the mandate of the organization and its plan to acquire funds to implement its key interventions.

Once the assessment is complete, a team of reviewers meets with the host organization to discuss the results, using an accreditation tool to generate scoring across ITPC's accreditation framework and standards. (See Annexes D and E for more information about the accreditation process.)



# ANNEX E

## Accreditation process

GOAL 1	ASSESSING THE EFFECTIVENESS OF CLM COMPONENTS	
<p><b>Education</b></p>	<p>Capacity building</p>	<p>The organization regularly and effectively builds the capacity of its members:</p> <ul style="list-style-type: none"> <li>→ Clear informational and educational materials (such as fact sheets, presentations, training curricula and communications toolkits) about standards and how to measure “what is” (actual practices and experience) against “what should be” (intended or desired policies, protocols, plans)</li> <li>→ A process (a reading checklist with quizzes, online training portal or standard training workshop agenda) through which individuals can go through content and then document that they have absorbed the information and are now informed and competent</li> <li>→ A process (discussion groups, regular briefings or trainings) through which individuals can update their knowledge and continually learn and exchange new information so that their levels of knowledge are current and up to date</li> </ul>
<p><b>Evidence</b></p>	<p>Data collection and storage</p>	<p>The organization has an established mechanism to systematically and accurately collect data at designated sites, transmit and store data securely, and establish a system for oversight of data collectors:</p> <ul style="list-style-type: none"> <li>→ Evidence is <b>community-generated</b> (people know that they can and should collect evidence, know how to collect that evidence, and know how and where to post and share that evidence)</li> <li>→ Evidence is <b>independently generated</b> (i.e., not wholly reliant on one funder that has a specific bias or intent; collected and posted from multiple perspectives and accountable to multiple audiences and stakeholders)</li> <li>→ Evidence is <b>ethically generated</b> (i.e., protecting confidentiality, security, consent)</li> <li>→ Evidence is <b>routine, continuous and sustained</b> (i.e., not a snapshot but collected and posted over time, so becomes significant as something anticipated and comparative over time)</li> <li>→ Evidence is <b>widespread</b> (i.e., collected and shared from multiple sites or locations, so becomes significant as comparative)</li> <li>→ Evidence is <b>rigorous</b> (structured, systematically collected, reviewed, cleaned, synthesized, etc., so that it is a valid and reliable reflection of what is truly there)</li> <li>→ Evidence is <b>actionable</b> (i.e., that it documents “what is”, can compare with “what should be”, and is useful in developing recommendations and mobilizing coalitions and allies and persuading policy makers)</li> </ul>

GOAL 1 (CONTINUED)	ASSESSING THE EFFECTIVENESS OF CLM COMPONENTS	
<b>Evidence</b>	Ethical clearance and consent	The organization has acquired ethical clearance to collect data and obtained written or verbal consent from all respondents.
	Capacity of data collectors	The organization has the requisite number of data collectors, who have the necessary skills and training to collect information; a mechanism exists for oversight of data collection processes.
	Data capture and entry	The organization regularly and effectively transmits the data it has collected to a secure database.
	Data quality	The organization has the capacity to systematically perform quality audits on the data it collects.
	Data analysis	The organization has the capacity to systematically and accurately analyse CLM data.
<b>Advocacy</b>	Advocacy	<p>The organization is able to undertake advocacy actions and interventions using CLM data:</p> <ul style="list-style-type: none"> <li>→ People's <b>experience, skills and abilities</b> for understanding policy and advocacy issues; crafting advocacy goals, strategies, targets and messaging; organizing coalitions and allies; communicating effectively; and their access and credibility with decision makers or other targets of advocacy</li> <li>→ People's <b>independence</b>, with resources and support, to work across organizations and interests and sustain that work in visible, vocal ways over time, especially when change takes years of pushing against entrenched interests, deep structural challenges, and cycles of negotiation and confrontation</li> <li>→ <b>Community structures</b>, such as advocacy networks or coalitions, websites and social media channels, or dedicated advocacy staffing at organizations, through which people can communicate and work together over time</li> </ul>
	Communications	The organization has the capacity to increase its visibility and promote its work at the local, national, regional and global levels.
<b>Engagement</b>	Ownership	The organization has demonstrated community ownership, innovation and adaptability in implementation in the national context.
	Academic institution	The organization has strong partnerships with local academic/research institutions or hires skilled consultants/individuals to support data analysis.
	Community consultative groups	The organization has a functional community consultative group that has oversight of the CLM data and advocacy interventions.
	National integration	The organization is integrated into the national context, has established local and national partnerships to synchronize activities and avoid duplication, and is involved in the community consultative group and/or national technical forums.

GOAL 2	ASSESSING THE EFFECTIVENESS OF ORGANIZATIONAL SYSTEMS, POLICIES AND GOVERNANCE
Good governance and accountability	The organization practices good governance and ensures accountability.
Policies	The organization has established policies that govern operations.
Transparency	The organization's leadership demonstrates transparency in decision making and operations.
Leadership	The organization has a clear leadership and management structure.
Personnel	The organization has an adequate number of skilled staff members to implement its essential functions (such as programme, finance and M&E).
IT and technology	The organization possesses appropriate technology tools and platforms to support CLM implementation.



# ANNEX F

## Resource list

### GLOBAL AIDS STRATEGY



#### **UNAIDS. End Inequalities. End AIDS. Global AIDS Strategy 2021-2026.**

**VIEW / DOWNLOAD:** [https://www.unaids.org/sites/default/files/media\\_asset/global-AIDS-strategy-2021-2026\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/global-AIDS-strategy-2021-2026_en.pdf)

### UNAIDS CLM RESOURCES



#### **Establishing community-led monitoring of HIV services — Principles and process | UNAIDS**

**VIEW / DOWNLOAD:** <https://www.unaids.org/en/resources/documents/2021/establishing-community-led-monitoring-hiv-services>

*The French, Russian and Spanish versions of the community-led guidance document and the accompanying frequently asked questions are now available online.*

**FRENCH:** <https://www.unaids.org/fr/resources/documents/2021/establishing-community-led-monitoring-hiv-services>

**RUSSIAN:** <https://www.unaids.org/ru/resources/documents/2021/establishing-community-led-monitoring-hiv-services>

**SPANISH:** <https://www.unaids.org/es/resources/documents/2021/establishing-community-led-monitoring-hiv-services>





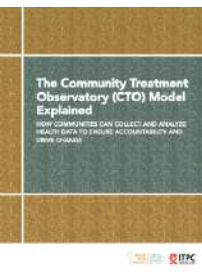
## Integrating Community-Led Monitoring (CLM) into C19RM Funding Requests

**VIEW / DOWNLOAD:** <https://itpcglobal.org/resource/integrating-community-led-monitoring-clm-into-c19rm-funding-requests>



## Community-led Monitoring Brief

**VIEW / DOWNLOAD:** [http://itpcglobal.org/wp-content/uploads/2020/02/Community-Led-Monitoring-Brief\\_full.pdf](http://itpcglobal.org/wp-content/uploads/2020/02/Community-Led-Monitoring-Brief_full.pdf)



## The ITPC Community Treatment Observatory (CTO) Model Explained

**VIEW / DOWNLOAD FULL REPORT:** <http://itpcglobal.org/wp-content/uploads/2019/02/ITPC-CTO-Model-Full-Eng.pdf>

**VIEW / DOWNLOAD SUMMARY:** <http://itpcglobal.org/wp-content/uploads/2019/02/ITPC-CTO-Model-Summary-Eng.pdf>



## Why We Must Watch What Matters: Initial Findings from the Regional Community Treatment Observatory in West Africa

**VIEW / DOWNLOAD:** <http://watchwhatmatters.org/wp-content/uploads/2018/03/RCTO-WA-Baseline-Summary-Report-2017.pdf>



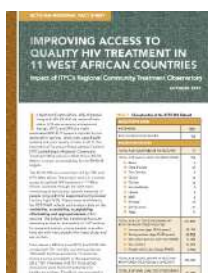
## Data for a Difference: Key Findings, Analysis and Advocacy Opportunities from the Regional Community Treatment Observatory in West Africa

**VIEW / DOWNLOAD:** <http://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>



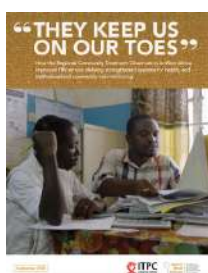
## **RCTO-WA Regional Fact Sheet: Understanding Gaps in the HIV Care Continuum in 11 West African Countries**

**VIEW / DOWNLOAD:** <https://itpcglobal.org/resource/integrating-community-led-monitoring-clm-into-c19rm-funding-requests>



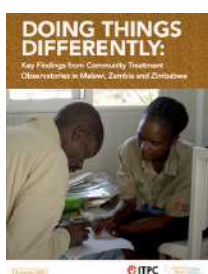
## **RCTO-WA Regional Fact Sheet: Improving Access to Quality HIV Treatment in 11 West African Countries**

**VIEW / DOWNLOAD:** <https://itpcglobal.org/wp-content/uploads/2019/10/RCTO-Regional-Fact-Sheet-2-English.pdf>



## **“They Keep Us on Our Toes”: How the Regional Community Treatment Observatory in West Africa improved HIV service delivery, strengthened systems for health, and institutionalized community-led monitoring**

**VIEW / DOWNLOAD:** <https://itpcglobal.org/wp-content/uploads/2020/10/ITPC-2020-They-Keep-Us-On-Our-Toes.pdf>



## **Doing Things Differently: Key Findings from Community Treatment Observatories in Malawi, Zambia and Zimbabwe**

**VIEW / DOWNLOAD:** [https://itpcglobal.org/wp-content/uploads/2020/10/saCTO-Analysis\\_9-21\\_rev2-2.pdf](https://itpcglobal.org/wp-content/uploads/2020/10/saCTO-Analysis_9-21_rev2-2.pdf)

## ITPC COMMUNITY TREATMENT OBSERVATORY VIDEOS



### **What is a Community Treatment Observatory? Short video**

**VIEW:** [https://www.youtube.com/watch?v=COY\\_4S\\_XFKI](https://www.youtube.com/watch?v=COY_4S_XFKI)



### **Watching What Matters: ITPC's Community Treatment Observatories**

**VIEW:** <https://www.youtube.com/watch?v=TxbI0dKUVzA>



### **Community-led monitoring can work anywhere in the world**

**VIEW:** [https://www.youtube.com/watch?v=rHAQGbT\\_MYI](https://www.youtube.com/watch?v=rHAQGbT_MYI)

## PEER-REVIEWED PUBLICATIONS ON ITPC'S COMMUNITY TREATMENT OBSERVATORY MODEL

**Baptiste S, Manouan A, Garcia P, Etya'ale H, Swan T, Jallow W (2020). Community-Led Monitoring: When Community Data Drives Implementation Strategies. *Current HIV/AIDS Reports*, 1-7.**

**VIEW / DOWNLOAD:** <https://link.springer.com/article/10.1007/s11904-020-00521-2>

**Ellie MP, Kibe PW, Flomo BM, Ngwatu BK (2019). Breaking barriers: Using evidence from a Community Treatment Observatory (CTO) to enhance uptake of HIV services in Sierra Leone. *The Journal of Health Design*, 4(1).**

**VIEW / DOWNLOAD:** <https://www.journalofhealthdesign.com/JHD/article/view/70>

**Oberth G, Baptiste S, Jallow W, Manouan A, Garcia P, Traore AM, Murara J, Boka R (2019). Understanding gaps in the HIV treatment cascade in eleven West African countries: Findings from a regional community treatment observatory. *Centre for Social Science Research (CSSR) Working Paper No. 441*. ISBN: 978-1-77011-428-9.**

**VIEW / DOWNLOAD:** <http://www.cssr.uct.ac.za/cssr/pub/wp/441>

## ITPC'S COMMUNITY TREATMENT OBSERVATORY CONFERENCE PAPERS



### **Abstract-driven session at IAS 2019 in July 2019, Mexico City, Mexico**

**VIEW / DOWNLOAD:** <http://programme.ias2019.org/Abstract/Abstract/2841>



### **Seminar at the Centre for Social Science Research, September 2019, University of Cape Town**

**VIEW / DOWNLOAD:** <http://www.cssr.uct.ac.za/event/understanding-gaps-hiv-treatment-cascade-11-west-african-countries-findings-regional-community>



### **Abstract-driven session at ICASA 2019 in December 2019, Kigali, Rwanda**

**VIEW / DOWNLOAD:** <https://www.professionalabstracts.com/icasa2019/iplanner/#/presentation/48>



### **Abstract-driven session at CROI 2020 in March 2020, Boston, Massachusetts**

**VIEW / DOWNLOAD:** <https://www.croiconference.org/abstract/improving-hiv-care-in-west-africa-effects-of-a-community-treatment-observatory>



### **Abstract-driven session at AIDS 2020: Virtual in July 2020**

**VIEW / DOWNLOAD:** <https://onlinelibrary.wiley.com/doi/full/10.1002/jia2.25547>

## COMMUNITY TREATMENT OBSERVATORIES IN THE PRESS



Independent observer  
of the Global Fund

### **Among Second Batch of Regional Concept Notes, A Community Approach to Treatment Access in West Africa**

**VIEW:** <https://aidspan.org/en/c/article/3526>



Independent observer  
of the Global Fund

### **Regional Community Treatment Observatory Catalyses Global Fund Investments West Africa**

**VIEW:** <https://www.aidspan.org/en/c/article/4971>



### **Leakages in ART treatment cascades in West Africa and Zambia**

**VIEW:** <https://www.aidsmap.com/news/aug-2019/leakages-art-treatment-cascades-west-africa-and-zambia>

## OTHER PUBLICATIONS WITH INFORMATION ON ITPC'S COMMUNITY MONITORING MODEL



### **UNAIDS (2019). Power to the People.**

**VIEW / DOWNLOAD:** [https://www.unaids.org/sites/default/files/media\\_asset/power-to-the-people\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/power-to-the-people_en.pdf)



### **UNAIDS (2020). Evidence for eliminating HIV-related stigma and discrimination.**

**VIEW / DOWNLOAD:** [https://www.unaids.org/sites/default/files/media\\_asset/eliminating-discrimination-guidance\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/eliminating-discrimination-guidance_en.pdf)

# ACKNOWLEDGEMENTS

The CLM UNAIDS Task Force (special thanks to **Carlos Garcia de Leon Moreno** and **Dasha Ocheret**), our national CLM community partners, **Sam Avrett, Solange Baptiste, Helen Etya'ale, Wame Jallow, Pedro Garcia, Alain Manouan, Keith Mienies, Gemma Oberth, Susan Perez, Nadia Rafif, Emmanuel Simon** and **Tracy Swan** contributed to this guide.



[admin@itpcglobal.org](mailto:admin@itpcglobal.org)



[/itpcglobal](https://www.facebook.com/itpcglobal)



[@itpcglobal](https://twitter.com/itpcglobal)



[@itpcglobal](https://www.instagram.com/itpcglobal)



[/itpcglobal](https://www.youtube.com/channel/UC.../itpcglobal)



[/company/itpcglobal](https://www.linkedin.com/company/itpcglobal)

## 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](https://itpcglobal.org).

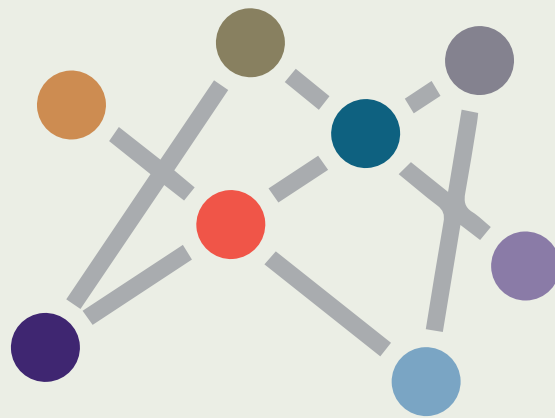
## ABOUT WATCH WHAT MATTERS

This publication is part of Watch What Matters, a community-led monitoring and research initiative to gather data on access to and quality of HIV treatment globally. To learn more, [visit our website](#), and use hashtag **#WatchWhatMatters** to join the global conversation.

## FOR MORE INFORMATION

To learn more about Watch What Matters and our community-led monitoring & advocacy work, contact [admin@itpcglobal.org](mailto:admin@itpcglobal.org).

**DESIGN AND ILLUSTRATIONS BY:** Trevor Messersmith, 80east Design



To read or download this publication in English, French or Spanish, click [itpcglobal.org/blog/resource/how-to-implement%20%26%20monitoring-toolkit/](https://itpcglobal.org/blog/resource/how-to-implement%20%26%20monitoring-toolkit/)

© COPYRIGHT ITPC DECEMBER 2021