Community-Led Monitoring of HIV, TB and Malaria Services in the Context of COVID-19

A Community Guide for Introducing Decision-Makers to Using CLM Data

ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

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Purpose of This Document

The purpose of this guide is to educate, orient, and sensitize different types of decision-makers about how to value and utilize Community-led Monitoring (CLM) data. By decision-makers, we refer to the various institutions and individuals who have the mandate and the authority to interpret and act on data or use data to drive decisions about programming, financing, and implementation that improve health programs and services. (See Figure 1 for a list of decision-makers).

Rationale

Too often, activities to support data use for CLM are missing or not prioritized, and do not include data quality assurance procedures to facilitate use in combination with larger data sets such as DHIS and HMIS. This can lead to limitations for joint data reviews and supervision visits. This document provides guidance for how communities might introduce CLM to a group of decision-makers to build their capacity, knowledge, and skills to:

- → Understand the scope, importance, and value-added of CLM data to national health programs
- → Reflect on how CLM data might be accessed and used for program improvement decisions
- → Assess readiness, capacity, and resource needs for CLM data use and develop plans to address gaps
- → Assess, track, and report on the use of CLM data
- → Consider CLM as a key contribution to national M&E systems and program review processes

FIGURE 1 Decision-Makers

DECISION-MAKING AUTHORITIES

with a mandate and power to act on the data, for program improvement, such as:

- ✓ HEALTH SERVICE PROVIDERS
- ✓ SOCIAL SERVICE PROVIDERS
- ✓ MANAGERS AT FACILITY LEVEL
- ✓ MANAGERS AT PROGRAM & POLICY LEVEL
- ✓ TECHNICAL PARTNERS & FUNDING PARTNERS

RECIPIENTS OF CARE

(including individuals and communities)

Who Should Read This Guide

This guide is intended to be used by:

- → **All current implementers of CLM**
- → **Civil society and community groups who are interested in establishing or strengthening the use of CLM data in decision-making**
- → **Technical assistance providers supporting CLM initiatives**
- → **All those working to introduce CLM to new partners (Partners who may be new to CLM may include: ministries of health, governments, multilateral and bilateral funders, health center management teams)**

Abbreviations and Acronyms

CCG	Community Consultative Group
CLM	Community-led Monitoring
CCM	Country Coordinating Mechanism
COP	Country Operational Plan
DSD	Differentiated service delivery
GC7	Grant Cycle 7 (previously named New Funding Model 4)
HMIS	Health management information systems
HIV	Human immunodeficiency virus
ITPC	International Treatment Preparedness Coalition
PEPFAR	President's Emergency Plan for AIDS Relief
PrEP	Pre-exposure prophylaxis
M&E	Monitoring and Evaluation

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1. Introduction

Before CLM data collection can begin, all stakeholders must be engaged to learn about what CLM is, what data will be collected, and the intended purpose of the work.

Otherwise, even well-structured CLM programs can be hindered by (a) skepticism and mistrust from stakeholders who have not been informed about CLM principles and practices; (b) related delays in securing approvals, Memorandums of Understanding (MOUs), Institutional Review Board (IRB) protocols and other forms of permission to collect data, and (c) missed opportunities for decision-makers to make use of CLM data, as they are not well-informed about the credibility and rigor of the CLM methodology.

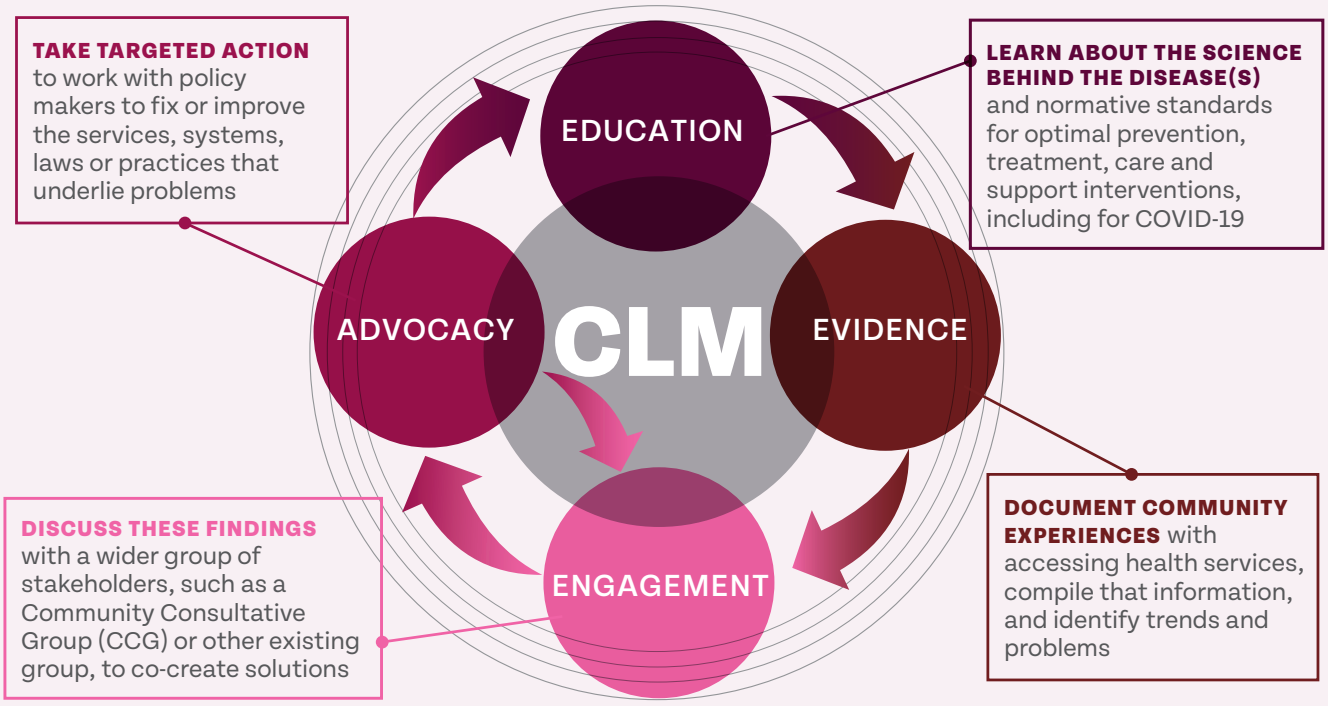
We encourage community organizations to make use of the clear and straightforward explanations below when preparing to present CLM to decision-makers for the first time.

1.1 What is community-led monitoring?

Community-led monitoring (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 their most important issues, undergo training to collect data and analyze 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 (See Figure 1).

CLM is a community-led effort that fills data gaps in national health information systems by leveraging the unique perspectives of affected communities and service users. It makes services more responsive by engaging communities and service users to identify and solve practical issues in program quality and advances participation, equity, and human rights.

FIGURE 2 The ITPC Community-led Monitoring Model



To download the ITPC CLM Implementation Toolkit and other resources, visit **CLMHUB.org**

CLM can help to:

- ✓ Improve service availability, accessibility, affordability, and quality
- ✓ Improve provider competency
- ✓ Improve procurement and supply management to prevent stock outs
- ✓ Improve public education messaging
- ✓ Improve allocations and expendures of government funding

Four essential components of CLM are the following:

- → **EDUCATION:** Communities review and prioritize their concerns with services, programs, and policies, and define the specific focus of their monitoring efforts.
- → **EVIDENCE:** Individuals systematically monitor and report on how services, programs, and policies are implemented and experienced by communities and recipients of care, compiling evidence that includes both quantitative (numerical) and qualitative (descriptive) measures.
- → **ENGAGEMENT:** Community organizations work alongside recipients of care, service providers, program managers, and policymakers to review and analyze the resulting CLM data to identify opportunities for improvement.
- → **ADVOCACY:** Community organizations leverage the results of their analysis to work with policymakers to fix the services, systems, laws, or practices that are creating the problem.

1.2 Core principles of CLM

CLM has core principles for achieving impact and avoiding common implementation and governance challenges. Organizations working with decision-makers should use these principles and promote them when training, educating, and sharing information to influence the use of CLM data in decision-making. Table 1 provides the eight core principles of CLM laid out in the White Paper, *Community-Led Monitoring: Best practices for strengthening the model*, that clarifies the principles behind community-led monitoring of health services.

TABLE 1 Core principles of CLM

Community-Led Monitoring must:	
1	**Be led by directly-impacted communities,** including people living with HIV, TB and/or malaria and key populations;
2	**Maintain local leadership and independence,** protecting against programmatic interference from other actors including donors, national government, and other monitoring and evaluation systems;
3	**Be owned by communities in every stage,** including identifying priority issues in the community, defining indicators, establishing preferred channels of communications with partners, and deciding how data are housed and used;
4	**Include advocacy activities aimed at generating political will and advancing equity,** given CLM's fundamental function as a social accountability tool;
5	**Adhere to ethical data collection, consent, confidentiality, and data security.** Data collection must be verifiable, reliable, conducted in a routine/continuous cycle and collected under 'do not harm' principle;
6	**Ensure that data are owned by communities, with programs empowered to share CLM data publicly and at their discretion.** CLM programs should not be made to re-gather, replace, or duplicate M&E data from existing systems;
7	**Ensure community monitors are representatives of service users,** and that they are trained, supported, and adequately paid for their labor, while maintaining the community independence from the donor;
8	**Be coordinated by a central, community owned structure** capable of managing the programmatic, financial, and human resource components of the program.

SOURCE: White Paper, *Community-Led Monitoring: Best practices for strengthening the model*

2. Barriers and Challenges Related to CLM Data Use by Decision-Makers

In March 2022, ITPC facilitated a process to gather feedback on barriers and challenges related to CLM data use.

The consultation started with a broad survey disseminated via Alchemer to 157 stakeholders, including CLM implementers and decision-makers; of whom 46 responded. Following the survey, ITPC held focus group discussions and key informant interviews to gather in-depth feedback. Of the 20 stakeholders who expressed interest in contributing to these, 14 were able to participate and represented the regions of West Africa (Côte d'Ivoire, Sierra Leone), Southern Africa (Malawi, Botswana), Asia (India, Nepal, Indonesia), and Latin America and the Caribbean (Guatemala, Jamaica).

While the scope and geographic spread of CLM initiatives is increasing, and large amounts of valuable information are being generated, CLM data are not yet being utilized to their full potential for program improvements and other actions to address the needs of affected communities. Stakeholder consultations revealed that both CLM implementers and decision-making authorities face challenges in CLM data use at different levels through the data journey.

The stakeholders noted barriers and challenges to CLM data use specific to decision-making authorities (for a full account on barriers including other stakeholders, ie, implementers, please refer to the ***Guide to Support CLM Data Use in Decision-Making***). Table 2 includes barriers identified by stakeholders, and recommendations presented to address those challenges.

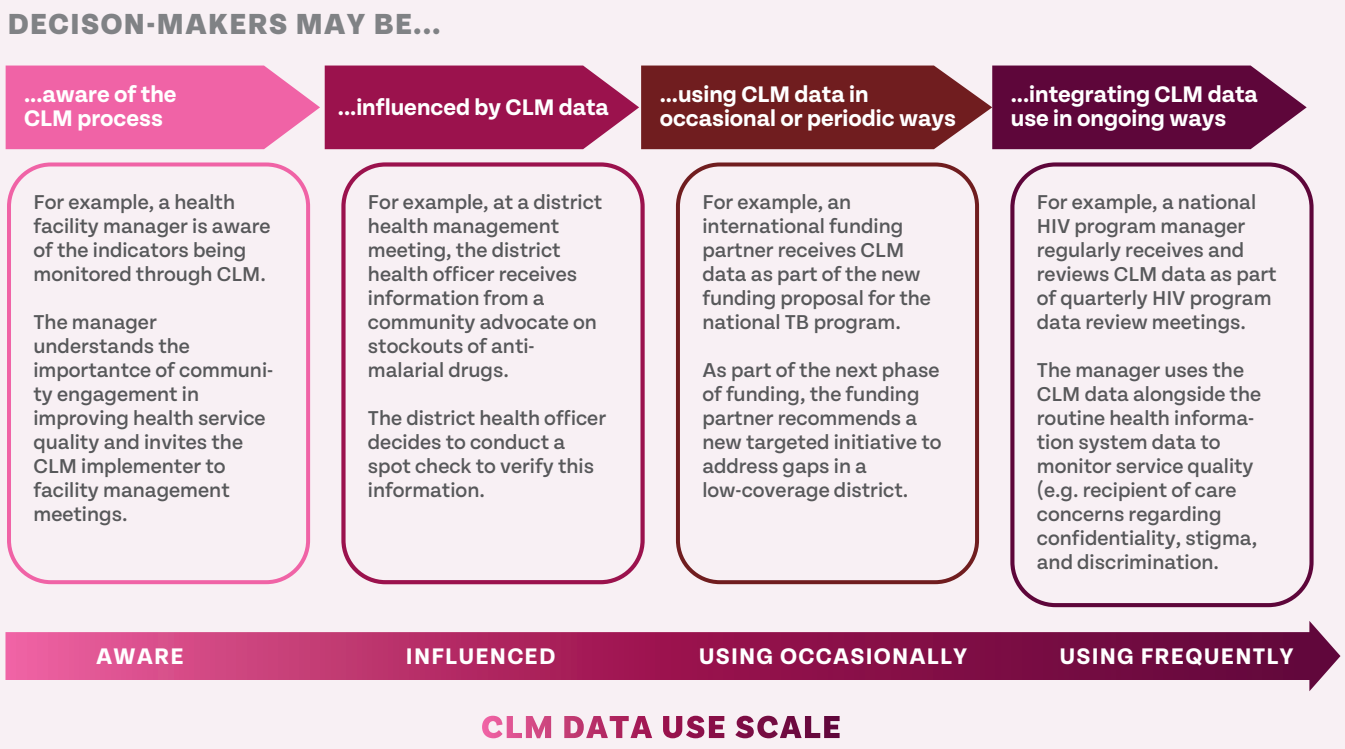
TABLE 2 Barriers and challenges to use of CLM data for decision-making – and actions to address them

BARRIERS AND CHALLENGES	ACTIONS TO ADDRESS BARRIERS
Decision-making authorities are not familiar with CLM: CLM is a relatively new and growing field in program monitoring, and many stakeholders note that it remains unknown, undervalued, and unfunded. In particular, decision- makers may not have training or an understanding of the value of qualitative data. As a result, CLM data, which include a significant qualitative component, are rarely considered in the development of program policies, guidelines, planning, and, most importantly, in understanding problems in the availability, accessibility, acceptability, and quality of health services.	→ **Train, educate, and inform decision-makers about CLM,** its importance, and its value to shaping and developing program policies, guidelines, planning, and in understanding problems regarding the availability, accessibility, acceptability, and quality of health services.
Decision-makers have different levels of awareness about CLM data and how it can be used to improve policies: Program managers and policy makers are not always quickly responsive to evidence and may need support for a gradual process of awareness, acknowledgement, and acceptance.	→ **Do not assume all players understand CLM.** Always begin CLM implementation with a kick-off meeting for a broad cross-section of stakeholders, including decision-makers, that provides a basic level of "CLM 101" education. This sensitization training about the importance and value of CLM data helps set the stage for CLM data to be meaningfully incorporated into the development of program policies, guidelines, and planning.
Decision-making authorities have concerns about data quality: Government and other decision-making authorities often express concerns about the quality of data generated by CLM processes. They may interrogate the legitimacy, reliability, and representativeness of the data by questioning whether the coverage of CLM activities geographically or across sub-populations is sufficient. In some instances, decision-makers may dismiss CLM data, raising questions regarding whose data counts and whose voice is heard.	→ **Educate decision-makers on the CLM data journey and data quality due to the rigor of this process.** Reinforce the power of CLM data to: monitor local service quality and access issues that are preventing programs from achieving their goals; adjust services, programs, and policies; and protect and promote human rights. CLM is complementary to other data used by decision-making authorities for program planning and improvement. It adds value to national health information systems.

BARRIERS AND CHALLENGES	ACTIONS TO ADDRESS BARRIERS
Service providers show resistance to use CLM data: At the local level, service providers may perceive CLM with suspicion due to its "watchdog"-type role and may feel that the process implicitly criticizes them or their work, rather than viewing CLM as a process where communities and service providers would work together to improve services for recipients of care.	→ **Engage service providers early in the CLM process** and establish data-sharing processes that enable use of CLM data to understand and respond to programmatic gaps.
CLM focus areas and indicators may be misaligned with those of national programs, donors, and partners: CLM implementers find that where CLM indicators are not aligned with national program targets, this results in a missed opportunity to use CLM data to identify the underlying barriers and root causes of missing these targets (for example, stigma impacting treatment adherence). CLM areas of focus, indicators, and reporting requirements may also not align with those of donors and partners. CLM implementers feel frustration that their voices may not be adequately heard in instances where donors show inflexibility about using these data.	→ **Explain the complementarity of CLM indicators as adding recipient-of-care perspectives to an issue for a more comprehensive understanding.** CLM indicators are defined by communities to monitor and address the issues and problems they have identified, rather than defined by outside actors, but it can be useful to draw connections between frameworks. For example, data in national health information systems (e.g., decreasing rates of treatment adherence) may be linked to trends identified in CLM data (e.g. long wait times, drug stock-outs, draconian COVID-19 lockdown measures with strict curfews that hinder access to HIV services). The golden ticket of CLM is the nuanced community-level insights that can help unpack and identify the root causes that are driving trends in district and national health information systems, and allow collective action to pinpoint and address problems more quickly.

The extent to which decision-makers will use data for action depends on their willingness and capacity. Data use can be thought of incrementally along a continuum of data use (Figure 3). For example, at a minimum, decision-makers may be simply aware of CLM data and influenced indirectly by the CLM process. Further along the continuum, decision-makers may be influenced by the findings and start to use CLM data in occasional or periodic ways, leading eventually to the integration and use of CLM data in their work on a regular and sustained basis.

FIGURE 3 Continuum of CLM data use from awareness to integrated use



3. Engagement by Decision-Makers

Engagement develops from partnerships between a variety of stakeholders; it provides communities, healthcare providers, and decision-makers 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, decision-makers can participate in meetings with CLM implementers and health facilities where data are reviewed, and thereby gain information needed to co-create solutions to address gaps in treatment and service delivery (see Figure 4).

Decision-making government officials should have a plan and process to routinely participate and receive information from CLM implementers. For example, decision-makers should participate in meetings with community consultative groups (CCG). The CCG is a multistakeholder technical advisory board that provides essential support and is made up of representatives from national networks of people living with HIV, key populations, and recipients of care. The CCG contributes to data collection tools, supports the implementation of CLM, helps with data analysis, and gives direction on organizational decisions. **During CCG meetings, communities and decision-makers strategize about ways to address issues and solve problems.**

FIGURE 4 Examples of methods for sharing/receiving CLM data analyses and findings

Location-Specific Meetings

- Health facility advisory committees
- CLM data review committees
- Community consultative groups (CCGs)
- Local community presentations and discussions

Country-Level Meetings

- Country dialogues, such as through Global Fund CCMs or PEPFAR COP processes
- Task force meetings about the specific issues and priorities being monitored by the CLM
- CLM-specific coordinating mechanisms such as OneGroups and People's COPs

Direct Reporting

- Agreements with CLM implementers to provide monthly or quarterly reports

Public Communications

- Academic partner reports and peer-reviewed journal publications
- Public media articles and broadcasts
- Messaging and infographics distributed through social media, email, and mobile phone applications
- Posting on publicly accessible CLM data websites
- Community journalism

4. Taking CLM-Informed Actions

Service providers and managers at health facilities can use the data to understand local service quality and access issues that are preventing programs from achieving their goals; adjust services, programs, and policies; and protect and promote human rights.

Technical partners and funders can use the data to obtain a more complete picture of the quality and impact of programs alongside other data sources, and allocate resources to address the issues. Decision-makers can identify potential solutions in collaboration with CLM implementers, define concrete actions, and allocate adequate resources to implement those actions.

4.1 What kind of actions can you take with CLM data?

At the local level, decision-makers and health and social service providers can take many actions based on CLM data. Figure 6 provides some examples of actions at the local level and Figure 6 provides ideas about actions at the national level that may come from using CLM data.

FIGURE 5 Possible actions informed by CLM Data (Local Level)

CLM USER	WHAT KINDS OF ACTIONS COULD YOU TAKE?
HEALTH AND SOCIAL SERVICE PROVIDERS	→ **Improve local service quality issues** to address immediate barriers related to service availability, accessibility, acceptability, quality, cost, and affordability, and concerns about confidentiality, discrimination, human rights violations, and gender issues. → **Sensitize or train service providers** on non-stigmatizing, culturally- and gender-sensitive, people-centered care. → **Adjust or decentralize service provision and program delivery** to improve engagement, retention, and positive outcomes of all, including marginalized and vulnerable populations and all genders.

FIGURE 5 Possible actions informed by CLM Data (LOCAL LEVEL)

CLM USER	WHAT KINDS OF ACTIONS COULD YOU TAKE?
MANAGERS AT FACILITY LEVEL	→ **Adjust policies, programs and service provision at the intermediate and central levels** – for example, adjusting service hours, redistributing staffing assignments, and updating trainings. → **Organize trainings to sensitize service providers** about non-stigmatizing, gender-sensitive, and people-centered care, including refreshers about standards of care, protocols and policies to improve quality of care. → **Request support** from expert community organizations to ensure that sensitization trainings are culturally and gender sensitive. → **Improve coordination and collaboration** across programs and sites.

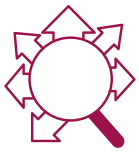
FIGURE 6 Possible actions informed by CLM Data (NATIONAL LEVEL)

CLM USER	WHAT KINDS OF ACTIONS COULD YOU TAKE?
MANAGERS AT POLICY & PROGRAM LEVEL (including health program and data/M&E experts, and other sectors)	→ **Allocate resources in country funding proposals** to achieve greater equity, quality, and effectiveness of existing services and programs and to create new targeted initiatives. → **Improve coordination and collaboration** across programs and sites. → **Develop and mandate sensitization and training programs** for service providers to ensure non-stigmatizing, culturally- and gender-sensitive, people-centered care. → **Adjust policies, programs, and services** to address identified gaps, disparities, and population needs.
TECHNICAL PARTNERS & FUNDING PARTNERS	→ **Provide funding and technical assistance** to support quality and effectiveness of existing services and programs and to fund new targeted initiatives to address identified gaps, disparities, and population needs.

5. Examples of Successful Use of CLM Data

CLM works. There are many examples of successful use of CLM data by decision-makers.

Figure 7 includes a summary of seven countries where decision-making authorities used CLM data for co-creating solutions, from eliminating user fees to working with clinics to improve policies and protocols for PrEP multi-month dispensing and condom distribution. Successful use of CLM data has come in settings where:



CLM IMPLEMENTERS have built capacity by gaining skills, experience, and resources for:

- → Data analysis and synthesis of findings and recommendations
- → Creation of visualizations and communications materials
- → Presenting data to service providers, program managers, and policymakers

SERVICE PROVIDERS have understood CLM data as evidence that can be used to improve service outcomes and impact.

GOVERNMENTAL AUTHORITIES have understood how CLM data can be high quality and additive to other routine country health information systems.

FIGURE 7 Examples of successful use of CLM data

CÔTE D'IVOIRE

The Ministry of Health used CLM data to eliminate user fees charged to PLHIV and to improve health sector governance, laboratory systems, and health management information systems (HMIS) and M&E.

MALAWI

Managers at the Ministry of Health used CLM data to justify expansion of working hours at public hospitals and increased resources for HIV testing during the COVID-19 pandemic.

MAURITANIA

Communities met with HIV service providers and the Ministry of Health to resolve issues and disparities in health commodity supply and access and the potential improvements to be made in availability, accessibility and acceptability.

SIERRA LEONE

The Government of Sierra Leone has used CLM data in introducing differentiated service delivery (DSD) to better reach key populations, and toward improvements in procurement, supply and management of HIV and TB medicines and commodities.

SOUTH AFRICA

The West Rand district health department used CLM data to work with clinics to improve policies and protocols for PrEP multi-month dispensing and condom distribution.

UKRAINE

Across seven regions, the Alliance for Public Health responded to 775 human rights violations with direct legal and psychosocial support and used the CLM data to work with decision-makers for development of appropriate national human rights strategies.

ZIMBABWE

Government officials at the Ministry of Health used CLM data to reduce the duration of stockouts of HIV medicines and HIV test kits.

6. Checklist for Assessing Readiness to Use CLM Data

Decision-makers should review the checklist provided below to assess their readiness to take informed actions based on CLM data. The results can guide decision-makers what actions to prioritize in their efforts to make the most of the nuanced community-level insights afforded by CLM data and analysis.

DECISION-MAKERS	CHECKLIST
 **SERVICE PROVIDERS**	✓ Are we willing to engage with CLM implementers to co-create solutions to address the identified barriers and challenges? ✓ Do we have enough background information to interpret these data in their context? ✓ Do we have enough background information to interpret these data in their context? ✓ How regularly do we receive information updates from CLM implementers? ✓ How will we track whether we have implemented the agreed actions? ✓ How will we assess the outcomes and impact of these actions? ✓ Are we in touch with the communities doing the work? ✓ Are we integrating CLM data into our regular monitoring/ reporting processes? ✓ CLM data changes over time – are we meeting with communities regularly for briefings? ✓ How can future CLM tell us more? ✓ Are the findings within my or my department's responsibility or purview? ✓ Are the findings potentially relevant to current initiatives to improve program and service performance? ✓ Are the findings potentially applicable to program and staff management and funding?

DECISION-MAKERS	CHECKLIST
 **MANAGERS AT FACILITY LEVEL**	✓ Are we willing to engage with CLM implementers to co-create solutions to address the identified barriers and challenges? ✓ What is our willingness and capacity to use CLM data for concrete action? ✓ What are our barriers to the use of CLM data in regular and ongoing ways? how can these be overcome? ✓ Do we have enough background information to interpret these data in their context? ✓ How regularly do we receive information updates from CLM implementers? ✓ How will we track whether we have implemented the agreed actions? ✓ How will we assess the outcomes and impact of these actions? ✓ Are we in touch with the communities doing the work? ✓ How can future CLM tell us more? ✓ Are the findings within my or my department's responsibility or purview? ✓ Are the findings potentially relevant to current initiatives to improve program and service performance? ✓ Are the findings potentially applicable to program and staff management and funding?
 **MANAGERS AT PROGRAM & POLICY LEVEL**	✓ What is our willingness and capacity to use CLM data for concrete action? ✓ Do we understand the key findings and messages that are being presented to us? ✓ Do we have enough background information to interpret these data in their context? ✓ How regularly do we receive information updates from CLM implementers? ✓ How will we track whether we have implemented the agreed actions? ✓ How will we assess the outcomes and impact of these actions? ✓ Do we know what CLM is taking place in our country/district/region? ✓ CLM data changes over time – are we meeting with communities regularly for briefings? ✓ How can future CLM tell us more? ✓ Any applicability to law, policy, and guidelines development?

DECISION-MAKERS	CHECKLIST
 **TECHNICAL PARTNERS & FUNDING PARTNERS**	✓ Do we understand the key findings and messages that are being presented to us? ✓ Do we have enough background information to interpret these data in their context? ✓ How will we track whether we have implemented the agreed actions? ✓ How will we assess the outcomes and impact of these actions? ✓ Do we know what CLM is taking place in our country/district/region? ✓ Are communities part of our drafting committees for COPs/GC7? ✓ How can future CLM tell us more? ✓ Any applicability to law, policy, and guidelines development?
 **HEALTH SERVICE PROVIDERS**	✓ What are our barriers to the use of CLM data in regular and ongoing ways? how can these be overcome?

Takeaway Message

Before CLM data collection can begin, all stakeholders must be engaged to learn about what CLM is, what data will be collected, and the intended purpose of the work.

While CLM can sometimes be misunderstood as a "fault-finding" activity, in reality, nuanced information and analysis from recipients of care have been vital for assessing and improving the efficacy of national M&E systems. Though activities supporting CLM data use for decision-making are often underprioritized, **this information can enable decision-makers to prioritize targeted and impactful health systems improvements for all.**

For More Information

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ITPC
INTERNATIONAL TREATMENT PREPAREDNESS COALITION

Watch What Matters

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About ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars:

- → **Build Resilient Communities (#TreatPeopleRight)**
- → **Intellectual property and access to medicines (#MakeMedicinesAffordable)**
- → **Community monitoring and accountability (#WatchWhatMatters)**

About Watch What Matters

Watch What Matters is a community monitoring and research initiative that gathers data on access to and quality of HIV treatment globally. It fulfills one of ITPC's core strategic objectives, to ensure that those in power remain accountable to the communities they serve.

Watch What Matters aims to streamline and standardize treatment access data collected by communities – helping ensure that data is no longer collected in a fragmented way and that it reflects the issues and questions that are most important to people living with and affected by HIV. It relies on a unique model that empowers communities to systematically, routinely collect and analyze qualitative and quantitative data on access barriers and shortfalls in quality of care and treatment and use it to guide advocacy efforts and promote accountability.

To learn more about Watch What Matters and our community-led monitoring work, visit www.WatchWhatMatters.org or send us an email at admin@itpcglobal.org.

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