

Community-led monitoring National Framework, Ethiopia

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MINISTRY OF HEALTH - ETHIOPIA

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HEALTHIER CITIZENS FOR PROSPEROUS NATION

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARVs	Anti-Retroviral Drugs
AYLHIV	Adolescent and youth Living with HIV
CBOs	Community-Based Organizations
CLAW	Community-Led Accountability Working Group
CLM	Community Led Monitoring
CLO	Community Led Organization
CSO	Civil Society Organizations
COVID 19	Coronavirus Disease of 2019
CSOs	Civil Society Organizations
DIC	Drop-in Centers
DSDM	Differentiated service delivery model
EDHS	Ethiopian Demographic and Health Survey
FGD	Focus group discussion
FSW	Female Sex Workers
GF	The Global fund for HIV, TB and Malaria
GC7	Grant Cycle 7
HCT	HIV counseling and testing
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
HAPCO	HIV/AIDS Prevention and Control Office
HTS	HIV Testing Service
IDI	In-depth interview
ITPC	The International Treatment Preparedness Coalition
KII	Key informant interview
KP	Key Population
KPP	Key and priority populations
OIs	Opportunistic Infections
OPD	Out-patient Department

OST	Opioid Substitution Therapy
MAT	Medically Assisted Therapy
MOH	Ministry of Health
NEP+	Networks of Networks of HIV Positives in Ethiopia
NFM3	New funding model 3
NGOs	Nongovernmental Organizations
NNPWE	National Networks of HIV-Positive Women In Ethiopia
PEP	Post-Exposure Prophylaxis
PWID	People Who Inject Drugs
PLHIV	People Living With HIV/AIDS
PMTCT	Prevention of Mother-To-Child Transmission of HIV
RHBs	Regional Health Bureaus
S&D	Stigma and Discrimination
SRH	Sexual and reproductive health
STIs	Sexually Transmitted Infections
TB	Tuberculosis
TWGs	Technical Working Group

Glossary of Terms

The Term	Definition
Advocacy	Is the act of actively supporting, promoting, and working toward a particular cause, idea, policy, or group of people
Community-led organizations	Are entities for which most of the governance, leadership, staff, spokespeople, membership, and volunteers reflect and represent the experiences, perspectives, and voices of their constituencies, and which have transparent mechanisms of accountability to their constituencies.
Community-led monitoring	is a process in which infected and affected communities, their organizations, and networks, identify issues, collect, and analyze data, engage with stakeholders to co-create solutions, and advocate to improve access to and quality of HIV, TB, and Malaria services and protect human rights.
Confidentiality	relates to measures to prevent unauthorized disclosure of participants' information during storage, transfer, and use.
Data	refers to raw facts, figures, or information that are collected, stored, and analyzed for various purposes.
Engagement	Is the active involvement, participation, and collaboration of CLM stakeholders in the process of reviewing community-led monitoring findings, identifying gaps and barriers, co-creating solutions, developing and implementing action plans, and monitoring changes in service access and quality.
Feedback	is the information, comments, opinions, or observations provided to individuals, groups, or entities about their performance, behavior, actions, work, or outcomes.
Informed consent	is the process in which a researcher or a data collector informs participants about the study objectives, voluntary nature of participation, risks, and benefits of participation in the study and seeks the participant's written or verbal consent depending on the nature of the study. The
Privacy	refers to the right of individuals to control access to their personal information and to make decisions about how that information is collected, used, shared, and stored.
Security	is protection of data from inadvertent or malicious and inappropriate access by any person who is not a member of the study team.

Foreword

The multi-sectoral and social nature of the HIV epidemic highlights underlying critical social and programmatic situations and circumstances which, if not addressed, can diminish efforts to maximize the reach and impacts of Ethiopia's HIV/AIDS response. The successful implementation of programs to address the HIV/AIDS epidemic requires prompting joint responses from multiple levels of the communities.

Community led monitoring is a critically important evidence-informed mechanism of empowering the local community to enhance their greater engagement in the HIV response.

In Ethiopia, Small scale implementation of community-led monitoring at key and priority population friendly clinics revealed the need for scale up and standardization, establishment of strong coordination structure and robust designing to enable identification, tracking and addressing barriers of access and quality to services at all levels. To effectively implement CLM initiative in Ethiopia, it is imperative to develop and standardize the national framework in line with evidence-based recommendations.

The MoH believes that this National CLM framework will play an instrumental role to provide guidance and standardize endeavors related to integrating user priorities and experiences into design of quality services through engagement of affected communities and meeting their needs.

Information obtained from CLM will be complementarily utilized along with national health management information systems. It will be triangulated with the available data to improve overall implementation, to provide more comprehensive picture of the service delivery and mitigate programmatic risks.

All stakeholders particularly the local communities and the CSOs are urged to utilize this national framework for consistent identification, documentation, and advocacy of barriers in accessibility, acceptability, affordability and quality HIV prevention and treatment services and the program.

It is my sincere hope that proper utilization of this national CLM framework, alongside other areas covered in the national strategic plan, will go a long way in empowering local communities for meaningful engagement in the HIV response in Ethiopia.

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1. Introduction

1.1. Background

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 prioritized 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 identified 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 [1].

The strength of CLM rests in that it is owned and conducted by people affected and infected with HIV, and civil society organizations closely working with these people. CLM uses the power of people living with HIV and key and priority 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 [1].

A strong governance structure is key for enabling CLM programs to solicit funding, manage staffing and other start-up steps, and ensure the successful implementation of the project. Implementation and governance led by people living with and impacted by HIV, community-led organizations, key populations, and other service users [2].

Globally, most CLM programs (82%) monitor indicators related to HIV, and 74% include TB indicators. Less commonly, 62% monitor indicators related to human rights, and 49% monitor COVID-19 indicators. Only 28% of programs include monitoring of malaria indicators [2].

Practice in 30 counties documented that CLM increased local organizations' capacity to collect and analyze data and conduct advocacy [3]. CLM helps to reduce stigma and human rights violations and increase access to and quality of HIV prevention, care, and treatment services [4, 3].

Ensuring quality of care has been a continued challenge to HIV services in Ethiopia [4]. The Second Stigma Index Survey in 2021 reported that 30% of PLHIV and key populations in Ethiopia face stigma and discrimination in healthcare settings. About 20% of PLHIV reported HIV testing without proper informed consent and 7% of PLHIV reported HIV status disclosure without consent in the healthcare settings [5]. Though there is significant stigma, unconsented care, and disclosure in healthcare settings

there were limited mechanisms to monitor stigma and human right violations in healthcare settings [6]. CLM could play a very critical role in monitoring quality of HIV, TB, and Malaria services and stigma and human rights violations in healthcare and community settings.

National HIV strategic plan 2023/24-2026/27 defined community-led monitoring (CLM) as a process through which communities systematically and routinely collect and analyse data at policy and strategy, programming, and service delivery levels to identify key bottlenecks and barriers. The CLM data collected at the policy and program level will help to ensure accountability and address barriers. When implemented at the health facility and community level, community-led monitoring can provide deep insights on targeted action to improve patient experience and the overall quality of care, resulting in better health outcomes for individuals and the broader community [7].

NSP 2023/24-2026/27 identified the following activities to be implemented to strengthen community-led monitoring in Ethiopia during the strategic period [7]:

- Establish a CLM task force at national and regional levels which will oversee the conceptualization and design of the CLM and review and act on CLM findings.
- Develop CLM national strategy, guidelines, and data collection and compilation tools to monitor, identify and address policy, program, and service gaps and barriers.
- Avail digital tools and technologies for data management and storage.
- Build community capacity including training on CLM including digital CLM tools, human resource (staffing), technical (training) and technological and financial capacity.
- Adopt, implement and monitor a digital CLM platform.
- Provide technical assistance to CSOs leading CLM for the development of a data warehouse to bring CLM data from multiple sources.
- Provide a real-time CLM dashboard and response module for multiple stakeholders to take prompt action on the ground and to promote evidence-based decision-making.
- Perform an annual assessment of needs, issues, and impact of CLM activities.

CLM will be complementary to national health management information systems (HMIS). Together, the data can inform national strategic and operational planning for HIV program to improve overall implementation and mitigate programmatic risks. CLM data can also be compiled and triangulated with government data over time for a more comprehensive picture of access to and quality of services [7].

PEPFAR-Ethiopia has been implementing the Community-Led Monitoring (CLM) project since April 2021, this initiative has been carried out in collaboration with local and

community-based organizations, civil societies, and associations for people living with HIV (PLHIV), as well as women and youth-led organizations.

The PEPFAR Community-Led Monitoring (CLM) process is a collaborative effort spearheaded by local, community-based organizations, civil society groups, networks of key populations, individuals living with HIV, and other affected community entities. These entities work together to collect both quantitative and qualitative data on HIV services, identify gaps, and advocate for solutions in partnership with service providers and healthcare leaders.

Implementer's uses quantitative and qualitative indicators, CLM initiatives track a wide range of issues related to the accessibility, availability, equity, effectiveness, and quality of HIV service delivery. Input is gathered from various stakeholders, including recipients of HIV services (particularly key and Priority populations), clinic management, and healthcare providers. This input is collected in a systematic manner to drive action and change, fostering strong and sustainable relationships with healthcare leadership and other stakeholders. At its core, CLM embodies PEPFAR's person-centered approach by prioritizing communities, their needs, and their voices in shaping the HIV response. By placing communities at the forefront, CLM ensures that interventions are tailored to meet the unique needs of those affected by HIV, ultimately leading to more effective and impactful outcomes.

Since its inception, the CLM project has been operational in 10 regions and 155 sites, with the participation of 28 local organizations and implementers. These selected organizations have been actively involved in the implementation of CLM for at least one year.

Table 1 PEPFAR-Ethiopia CLM Implementation Geographic coverage and sites

s/n	Region	FY21/22 (Round 1)		FY23 (Round 2)		FY24 (Round 3) **		Cumulative (Total)	
		#IPs	#Sites	#IPs	#Sites	#IPs	#Sites	#IPs	#Sites
1.	Addis Ababa	3	9	3(1*)	6	5 (2@)	22	10 (2@)	37
2.	Afar	1*	3*	1*	3*	1*	3(2*)	1	4
3.	Amhara	2	10	2	9	5(3*)	26	6	45
4.	Dire Dawa	1*	3	1*	3	1	2	2	8
5.	Gambella	1*	2	1*	2	1*	5	1	9
6.	Oromia	2	4	3(1*)	7	1	2	5	13
7.	Sidama	1	10					1	10
8.	South Ethiopia	1	3			1*	4	1	7
9.	Somali			1	4			1	4
10.	Tigray					2	18	2	18

Total	12	44	12	34	15	78	28	155
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Note: *Same IP and/or site (deduct number with the sign while adding horizontally) **Ongoing (October 2023 – September 2024), @ IP implementing in two regions (deduct number with the sign while adding vertically)

Implementers collaborated closely with health facilities, community sites, and local health administrative offices such as woreda and zonal health offices. Prior to commencing the implementation of the CLM project, each implementer signed a Memorandum of Understanding (MOU) with the Health/HIV coordinating office, such as the regional health bureau or Zonal health department/office.

The focus areas under monitoring included the delivery of quality HIV services, access to HIV services, client satisfaction, client perspectives on privacy and confidentiality, client experiences with provider attitudes, adequacy of HIV information, working hours, waiting times, empowering communities to seek information and increase health literacy, addressing unmet needs, ART retention, strengthening community capacity to collect, analyze, and utilize data for improvement, enhancing client and community advocacy to assess and demand quality services, among others.

Overall, the collaboration between implementers and health offices aimed to improve the quality and accessibility of HIV services, empower communities, and enhance the overall health outcomes for clients.

The PEPFAR Community-Led Monitoring (CLM) program has been strategically focused on Key Population (KP) programs, integration with Quality Improvement initiatives, and fostering collaboration between facilities and communities. Through ongoing engagement with stakeholders, both quantitative and qualitative methods have been utilized to collect data on client experiences and identify factors that either enable or hinder service delivery.

Notable achievements stemming from the implementation of the PEPFAR CLM program include heightened client participation in CLM activities, the collection and analysis of community-level data to pinpoint gaps in care, the development of collaborative action plans involving implementing partners, service providers, and clients to address identified gaps, and the establishment of CLM Advocacy forums to address emerging issues. The CLM program also plays a crucial role in continuously monitoring service quality and implementing remedial actions as needed.

The Global Fund New Funding Model (NFM3) and Global Fund Cycle 7 (GC7) grants have funding to support implementation of CLM. However, there was no CLM framework to guide CLM implementation in the country.

1.2. Purpose and audiences of Community led monitoring National framework.

The purpose of community led monitoring national framework is to guide the establishment, coordination, implementation, and monitoring of community led monitoring in Ethiopia. The community led monitoring National framework defined the goal and objectives of community led monitoring in Ethiopia, the priority themes to be monitored and the priority population groups to be targeted. The CLM national framework defines the data collection methods, tools and ethical principles applied in CLM in Ethiopia. The CLM framework defines the governance structure for CLM implementation in Ethiopia at national and sub-national levels.

The National CLM framework aims to empower communities and people affected and infected by HIV to collect, analyses and utilize data to co-create solutions with the service providers and advocate to improve access to and quality of HIV services and protect human rights.

This national framework is intended to be used by all actors working on CLM and those responsible stakeholders have role in addressing the problems identified by CLM. The intended audience of the national CLM framework includes: -

- CLM coalitions at different levels
- CLM host organization(s)
- CLM implementers
- Health facility and community sites providing direct service to clients.
- Governance bodies: Ministry of Health, Regional Health Bureaus, Zonal and woreda health offices
- Partners, donors and funding organizations supporting CLM program.
- Affected and infected communities

1.3. Community-led Monitoring National framework development process

The CLM National framework was developed based on review of global guidance and experiences and various consultative processes with global, national and grassroots stakeholders.

In November 2023, a national CLM workshop was convened by the Ministry of Health through a collaborative effort of all stakeholders. This workshop brought together representatives from key populations, HIV civil society advocates, donors, technical agencies, governments, United Nations agencies, and other national and international pertinent stakeholders were involved.

Stakeholders were engaged in discussions on CLM during national strategic planning and the development of the Global Fund to Fight AIDS, funding request.

Desk reviews of global guidance and practices was conducted and a two-day consultative workshop in February 2024. The draft CLM national framework was enriched with stakeholders' inputs from a three-day validation workshop in March 2024.

2. Overview of Community-led monitoring (CLM)

2.1. What is community-led monitoring?

Community Led Monitoring (CLM) for HIV serves as an essential accountability mechanism across various tiers of HIV, responses. This approach is spearheaded and executed by local community-led organizations comprising individuals living with HIV, key & priority populations, and or community entities. CLM operates through a structured framework and employs rigorously trained peer monitors who systematically gather and analyze both qualitative and quantitative data pertaining to HIV service delivery. This includes data sourced from individuals within community settings who may not have regular access to healthcare facilities. Importantly, CLM establishes swift feedback channels with program managers and health policymakers. The data collected through CLM initiatives furnishes evidence on successful practices, areas requiring improvement, and identifies specific actions necessary for enhancing outcomes [1].

Through CLM process, community-led organizations, key and priority populations enhance their technical proficiency in data gathering, analysis, security, utilization, and ownership. CLM complements local and national monitoring efforts, bridging critical gaps in decision-making processes to inform evidence-based actions aimed at service improvement. CLM establishes a platform for strengthening partnerships with other stakeholders in the HIV/AIDS response, fostering a shared understanding and collaborative approach toward addressing service facilitators and barriers [1].

Moreover, CLM extends its utility beyond HIV-specific monitoring. It can effectively track service quality trends across various disease domains such as tuberculosis, malaria, and sexual and reproductive health. Additionally, it proves valuable in navigating humanitarian crises, navigating challenging environments, and evaluating social and structural health interventions, including combination prevention and human rights compliance, promotion, and protection. It is important to clarify that CLM serves a distinct purpose as a surveillance and accountability mechanism for health services. It should not be conflated with community-based HIV service delivery or routine collection and reporting of internal program data by community-led organizations [1].

2.2. Why Community-Led Monitoring Now?

The emergence of Community-Led Monitoring (CLM) can be attributed in part to the recognition by program planners and donors of the distinct value of community-

generated data in addressing the prevalent issue of interruptions in antiretroviral treatment among people living with HIV. As the number of individuals diagnosed with HIV and commencing treatment rises, there is a pressing need for services to adapt and become more user-friendly, especially for those initiating antiretroviral therapy early.

Although CLM is not a new concept, various forms of it have been utilized by communities to address issues such as stock-outs of antiretroviral medicines, service attitudes, and shortages of medicines for conditions like tuberculosis and viral hepatitis. The acknowledgment of CLM's unique contribution to ensuring the suitability of health services has led to increased investment and active promotion by international funders such as the United States President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis, and Malaria (Global Fund). United Nations (UN) agencies are also actively endorsing CLM as a means to advocate for equity and rights within HIV programs [1].

Substantial funding support enables community-led organizations and networks to formally demonstrate the value of their expertise and translate the profound knowledge, trust, and understanding they possess into tangible program enhancements. The global and normative acceptance of CLM encourages decision-makers to integrate the valid contributions of affected populations into efforts to enhance service quality and livelihoods more broadly. Moreover, the COVID-19 pandemic and its ensuing responses have underscored the barriers to collecting and transmitting data from service users to facilities, thus emphasizing the necessity for high-quality and systematic community data collection and analysis. CLM can extend its monitoring capabilities beyond HIV to encompass other disease areas such as tuberculosis, mental health, and sexual and reproductive health. It also proves valuable in humanitarian settings, challenging environments, and in monitoring societal and structural interventions aimed at improving the legal environment, promoting and protecting human rights, and combating stigma and discrimination. In these ways, CLM can advance the development of integrated, rights-based, and people-centered health systems, as well as more accountable supply chains, extending beyond the realm of HIV [1].

CLM has the potential to shape effective health services and influence policy changes integral to the pursuit of universal health coverage and tailored healthcare. Universal health coverage aims to ensure that all individuals and communities receive the necessary health services without encountering financial hardship. Meanwhile, tailored healthcare involves designing and delivering health services that consider factors such as location, health-seeking behavior, disease prevalence, and structural environments [1].

2.3. Experience with community-led monitoring.

Experience with community-led monitoring reveals its efficacy in effecting policy and practice changes at both local and national levels. For instance, the Ritshidze Project serves as a notable model of CLM implementation in South African communities, catering to nearly half of the country's population living with HIV. Collaboratively initiated by groups and organizations of people living with HIV, including the South Africa National AIDS Council Civil Society Forum and the Treatment Action Campaign, the project is supported by the Department of Health at various levels, UNAIDS, and funded by PEPFAR through grants from the United States Centers for Disease Control and Prevention (CDC) and USAID. Through this project, community teams engage in data collection and analysis, presenting their findings to facility management for collaborative problem-solving. Noteworthy improvements resulting from the project include enhanced access to medicines through multi-month dispensing, increased staffing levels, and reduced stigmatization of individuals missing appointments. Additionally regional groupings of community treatment observatories have been established in western and southern Africa, actively sharing successful methodologies, tools, and experiences. Notable achievements include the Data for a Difference project in western Africa, which links 11 country observatories led by networks of people living with HIV in the region. Regional data indicate reductions in stock-outs of antiretroviral medicines and viral load tests, as well as improvements in viral load suppression rates. Specific successes include policy changes in Sierra Leone, alterations to viral load monitoring data collection in Mali, evidence-informed dialogue leading to human rights strategies and gender-related barrier addressing in Ghana, and the elimination of user fees in Côte d'Ivoire [3].

The results and impact of initiatives like the Ritshidze Project in South Africa and similar endeavors in Western Africa played a pivotal role in demonstrating the efficacy of Community-Led Monitoring (CLM) and spurring expanded global interest and funding in this approach.

2.4. Key lessons from early CLM implementation.

Building trust among all stakeholders, including government entities, service providers, community groups, and sponsors, is paramount for the success of CLM. Achieving this requires transparent, consistent, and broad-based communication, as well as the development and implementation of sound policies [1].

Early engagement with health departments is essential. Top policymakers must recognize CLM as a valuable tool for achieving HIV-related goals, while local health service managers should view CLM as a collaborative partner in fulfilling their responsibilities [1].

While CLM often addresses service deficiencies, the focus should not be on assigning blame but rather on conducting a comprehensive analysis of contributing factors and collaboratively identifying solutions that meet user needs [1].

Formal collaboration between different networks of people living with HIV and community-led organizations from affected communities is the most effective CLM model for ensuring systematic processes and appropriate data collection. Early agreement among members of the CLM coalition on data collection topics provides the foundation and framework for future activities. Providing tailored and ongoing training for data collectors is crucial to ensure their confidence and competence in using all data collection tools effectively. Data collectors and other community members involved in CLM activities should be remunerated in accordance with national practices and standards. Sharing validated and appropriate standardized tools can alleviate the burden of establishing CLM. Established tools can be adapted to local contexts, and efforts are underway to establish a central resource repository through initiatives like those led by UNAIDS [1].

CLM can yield valuable data and drive beneficial action even without formal integration into the national monitoring platform. However, CLM data should eventually become part of the broader information structure without compromising community leadership. Communities should be the leaders of CLM and equal partners in decision-making processes regarding service quality. Non-community members with technical expertise can provide support and advice as needed [1].

Acceptance and integration of CLM into decision-making processes and negotiations with local authorities, funders, and other external supporters depend on collaborative efforts focused on problem-solving and credibility. Credibility stems from valid and useful data, combined with demonstrated community leadership and civic participation. A structured long-term plan for capacity-building, supervision, and performance feedback for data collectors, analysts, and advocates will optimize the results and impact of CLM [1].

3. CLM in Ethiopia, Strengths, Limitations, Opportunities and Treats (SLOT) analyses

The SLOT analysis was conducted by expert opinion and consultation of stakeholders in a two-day workshop .

Strengths

- The government committed to evidence-informed HIV program planning.
- There is a national strategic plan that provides guidance and strongly supports CLM implementation.
- National and Local government authorities are already engaging with communities on service provision for PLHIV, FSWs, PWID
- PLHIV Communities are organized in networks and associations and present at grass-roots levels with a common purpose and are working with government and donors.
- KPs have been working with health facilities and partners as peer service providers (peer navigators)
- CLM has been piloted and there is some experience and monitoring tools are ready to be adapted from existing CLM programs.
- Growing global momentum for a people-centered and community-led HIV response.
- Availability of key and priority population clinics at government healthcare delivery points
- Key and priority populations service packages, guidelines, and standard operation procedures.

Limitations

- There is no national CLM framework and guidelines that define CLM governance, methods, and tools.
- There is no CLM coalition independent of government. CLM coalition was not established.
- Limited capacity to implement CLM – staffing, knowledge, skill and experience on CLM among CLOs and CSOs

Opportunities

- Funding is available (GF, PEPFAR, UN etc)
- There are donors and partners ready to broker arrangements between government and CSOs/CLOs (UN, PEPFAR and other partners)
- Availability of technical support for capacity-building
- HIV and TB affected and infected communities of are knowledgeable about health service standards and structural enablers and barriers.
- Supportive policy and strategic frameworks
- Organized and accountable HIV service provision sites

Threats

- Undue influence and interference of government and donors in the process of CLM implementation
- Conflicts of interest among CLOs/CSOs and networks – hosts and implementers
- Lack of alignment between different supports (GF, PEPFAR and UN etc)
- Inadequate engagement and commitment of health facilities and programs for co-creation of solutions
- Refusal of data collection and overall CLM program at health facilities
- Diverse languages and cultures – need to adapt tools to different local languages.
- Poor quality data that hinder advocacy and momentum
- Misuse of systems and data collected at facility and community levels.

4. CLM Objectives and guiding principles

4.1. CLM Goal and Objectives

Goal: Ensure access to and quality of HIV services including protection of human rights of people infected and affected by HIV.

Objectives

- Enable communities, CLOs, and CSO networks to collect, analyze and use qualitative and quantitative data at health facility and community levels to co-create solutions and advocate to improve access to and quality of services, and enhance human rights.
- Ensure inclusion of clients' perspective in service quality management and program monitoring
- Build communities, CLOs, and CSO networks capacity on service standards, evidence generation, engagement, and advocacy.
- Enhance collaboration and accountability among communities, CLOs, CSO networks, government, partners, and donors.

4.2. Guiding Principles

- Community-led– Process owned and led by affected and infected communities and CLOs/CSOs.
- Independent: conducted independently and autonomously, without being directed or interfered with by other stakeholders (e.g., the government or a donor).
- Accountability: Collection and analysis of data through a lens of community need, identifying solutions, and holding decision-makers accountable for their implementation.
- Collaborative: Promoting good partnerships between all those involved in the service monitoring and improvement cycle—including the Ministry of Health, Regional health bureaus, zonal, woreda and town health offices, CSOs, partners, health facilities, and service providers
- Routine and systematic: CLM should be developed and funded sustainably to allow for ongoing systematic data collection, advocacy, and action that can monitor trends over time.
- Results and solution-oriented: The intended outcome of CLM is to achieve improvements collaboratively that respond to the community's priorities and improve health outcomes.

- Advocacy : The key component of CLM will be engagement and advocacy with key stakeholders such as MoH, RHBs, Zonal and woreda health offices and health facilities for co-creation of solutions
- Ethically governed: The ethical principles, autonomy, justice and beneficence, will govern the CLM design, data collection, reporting and use.
- Sustainability: Ensuring sustainability through building capacity, mobilizing domestic and donor resource and programmatic integration.
- Commitment: Government, partners, CLO, CSOs and service providers commitment to realize establishment, implementation, and sustainability of CLM is required
- Volunteerism: CLM shouldn't be only incentive based and should also include serving the community willingly and without paid to do it

5. The CLM Components, population, and thematic priorities

5.1. CLM Components

CLM covers four key areas: **education, evidence, engagement and advocacy.**

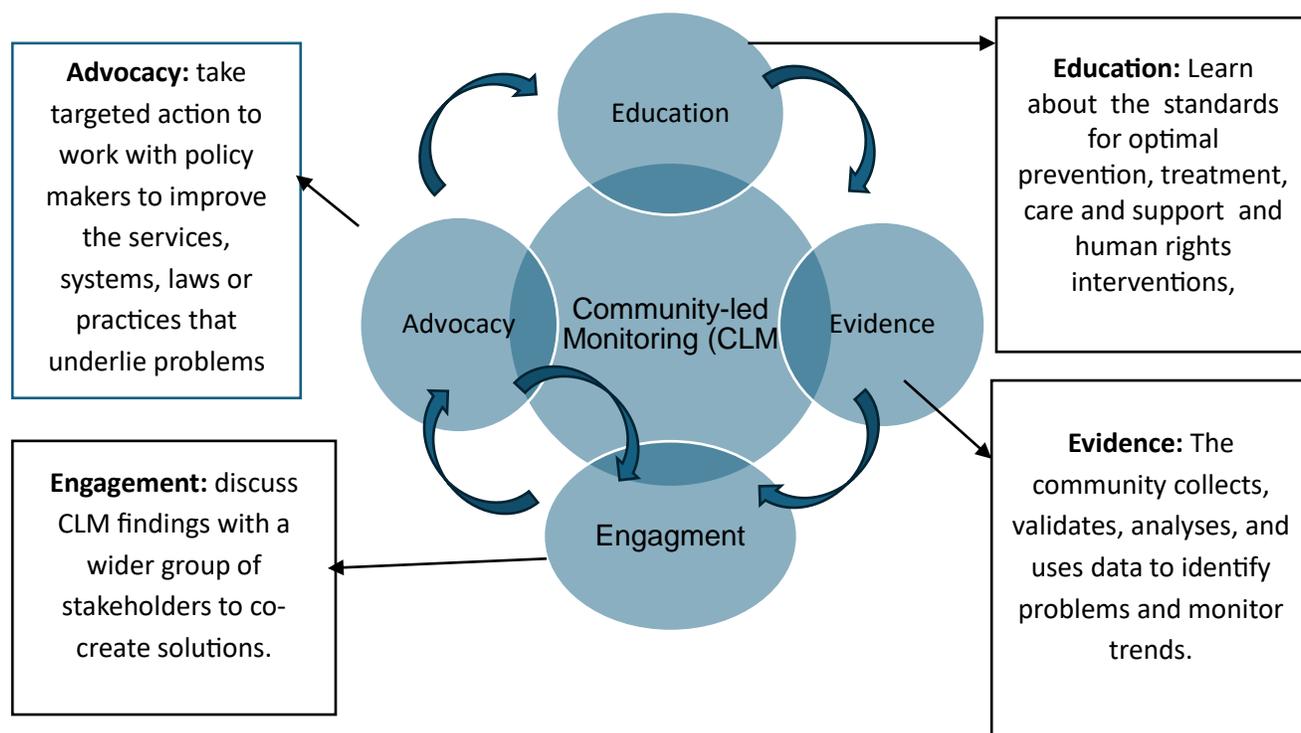


Figure 1 CLM components.

a. Education

Community led monitoring uses the national and global human rights and service delivery guidelines and standards as a bases to monitor human rights and services delivered to people affected and infected by HIV.

Education and training of people affected and infected by HIV as well as those organizations hosting or implementing CLM is fundamental for success of a CLM program. A CLM approach focused on HIV would include education and training around the targets and interventions of prevention, testing, care and treatment, and human rights issues. This education and trainings ensure that community members understand the services and treatment they are entitled to and are familiar with their national treatment guidelines. Education builds a strong, sustainable foundation for organizations that host and implement CLM and related advocacy.

Therefore, CLM related education and trainings to communities affected and infected by HIV and CLM host and implementing organizations should include targets and package of services for HIV and human rights in Ethiopia.

b. Evidence

Community led monitoring data collected from facilities and community sites are the evidence that informs solutions and advocacy. Gathering this evidence is often the most visible component of CLM. CLM systematically and routinely collects and analyze qualitative and quantitative data to co-create solutions and advocacy to improve access to and quality of services and human rights of communities affected and infected by HIV.

CLM evidence generation involves systematically and routinely collecting data, verifying, entering and cleaning it, data analysis (including monitoring for trends), and data quality audits.

c. Engagement

CLM is an effective way to solve problems collaboratively. CLM ensures engagement of key stakeholders to co-create solutions to improve access and quality of services and protect human rights of communities affected and infected by HIV. 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 develops from partnerships between varieties of stakeholders. CLM stakeholders are representatives from networks of people living with HIV, and key populations, officials from health care facilities and ministries of health, policy makers, donors, NGOs and academic partners.

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.

CLM establish rapid feedback loops with decision-makers at the program and health facility level. CLM implementers meet 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.

d. Advocacy

The purpose of CLM is to improve access to and quality of HIV prevention, care and treatment services and protect human rights of affected and infected communities through evidence-based advocacy. CLM aims to identify and advocate for innovations and good practices that can be sustained, replicated, and brought to scale.

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, and national levels.

When it is not possible to co-create solutions, communities, their organizations, and networks forge ahead to address their needs and hold decision-makers accountable, using watchdogging and/or participatory monitoring and accountability approaches.

5.2. CLM Populations Priorities

The population priorities for community-led monitoring in Ethiopia include:

- People living with HIV (PLHIV), especially HIV-positive children, adolescents, and youth.
- Female sex workers (FSWs)
- People who inject drugs (PWIDs)
- Prisoners
- High-risk adolescent girls and young women
- Workers in hot spot areas
- Distance drivers.
- High-risk Uniformed Personnel
- High-risk divorced and widowed men and women.
- HIV-negative sexual partners of PLHIV
- People in humanitarian settings

5.3. CLM Thematic Areas

The priority thematic areas for CLM in Ethiopia include the following:

- HIV service quality
- HIV services availability
- HIV services accessibility (distance, opening hours, availability of services, user fees, etc.)
- HIV services acceptability/friendliness of services including the implementation of differentiated service delivery models (DSDM) for HIV.
- Availability of HIV prevention, diagnosis, treatment, and monitoring products
- Sexual and reproductive health (SRH) services and counseling
- Human rights of people infected and affected by HIV including stigma and discrimination, unconsented care, unconsented disclosure, delayed and inadvertent disclosure, and gender-based violence.

- Psychosocial and economic care and support for people infected and affected by HIV.
- Supportive policy, legal and strategy frameworks, guidelines, and tools
- Coordination, leadership and partnerships
- Availability of resources (technical and financial) and utilization of funds

5.4. Scale of CLM

Community-led monitoring has been piloted for the last few years in selected facilities with PEPFAR support. The scale of implementation will reach an intermediate scale (up to 50 health facilities) across different regions in the next two years (2025). The implementation will be scaled to a national scale covering the 300 priority woredas in the next 5 years.

CLM will be implemented in public hospitals and health centers, CSO/NGO health facilities, drop-in centers, and Key and priority population-friendly clinics and other community programs.

5.5. Strategies to sustain CLM.

The following are the strategies to ensure the sustainability of CLM in Ethiopia

- Mobilize resources from communities, donors, and government to ensure the availability of funds to sustain CLM and related advocacy.
- Ensure the scale of the CLMs matches the available budget (the number of sites and indicators) and timely utilization of funds.
- Ensure integration of the CLM into national strategic and investment plans and policy documents
- Build capacity of CLM host and implementing partners. Ensure adequate investment in training and systems strengthening for HIV CSOs/CLOs networks.
- Ensure communities and CSOs' ownership of CLM - ensure that CLM is truly community-led and supported by national structures.
- Ensure CLM Coalition at all levels (national, regional, zonal, woreda) to function well and mobilize resources.
- Ensure that CLM is relevant – collects the right information, and timely provides evidence to co-create solutions with health facilities and advocacy at higher levels.
- Establish cross-learning and rewarding mechanisms for sharing experiences and scale up best practices in CLM implementation, advocacy, and problem-solving.
- Intergrade CLM use of CLM findings through existing platforms like review meeting

6. CLM Methods and Process

6.1. CLM Data Collection Methods

CLM in Ethiopia will use the data collection methods developed locally or adapted from pilot projects and other countries. Both qualitative and quantitative methods of data collection will be applied for CLM. One or more of the following quantitative and qualitative methods can be used:

- Exit interviews/user surveys – Surveys with clients using HIV services.
- Health facility record reviews with checklists.
- Observations of services at health facility and community levels including treatment observatories
- Focus Group discussion including Community scorecards.
- Key informant interview with service providers, facility heads, and other stakeholders
- Continues user feedback – I monitor and use client feedback mechanisms at health facilities (suggestion boxes and registers)
- Community-level surveys – door-to-door, institution-based, telephone, online, or android-based surveys, etc
- Review of secondary data including routine reports, minutes, supervision feedback, and survey findings to substantiate the primary CLM data.
- Use of routine registrations by community members

6.2. CLM Data Collection Tools

CLM in Ethiopia will use data collection tools developed locally or tools adapted from pilot projects and other countries. CLM tools shall be field-tested and approved by the CLM coalition at national and sub-national levels before it applied for CLM data collection. The CLM program will use digital /electronic data collection tools. The tools that can be used for systematic and routine CLM data collection can include one or more of the following:

- Structured survey questionnaires
- Health facility record reviews and observations with checklists.
- Key informant and Focus group discussion guides.
- I –Monitor client feedback electronic forms
- Other electronic data collection tools like ODK, Kobo collect, Compare, and Google Forms.

6.3. CLM Data Collection Process

CLM in Ethiopia should be a routine and systematic data collection. CLM applies scientific methods and tools, is routine to monitor trends over time, and continuously improves the HIV services and human rights of infected and affected communities.

Each CLM project should develop a CLM protocol that defines the details of sample size, sample selection, and data collection procedure. The CLM host and implementing organizations shall develop a CLM data collection, validation, analysis, and interpretation protocol. The CLM protocol shall define the frequency of data collection, participant selection, recruitment, consent, data confidentiality, and security measures. Data collectors and supervisors shall be trained on and use the CLM protocol in day-to-day data collection, analysis, and interpretation.

CLM data shall be collected by trained peer monitors who are infected or affected by HIV including PLHIV and key populations who speak the local language. The peer monitors (data collectors) shall be full /part-time staff with longer-term contracts. The CLM program shall build peer monitor capacity and retain them with an adequate incentive package.

6.4. Ethical Considerations

CLM shall uphold three ethical principles that include respect for Persons, beneficence, and justice for individuals and communities participating in CLM.

It is essential to ensure that all individuals who are participating in the CLM process are treated with respect and dignity. Individuals should be treated as autonomous (independent) agents. CLM data should use standard informed consent of participants. CLM informed consent process should be ensured.

- Voluntary participation
- Informed of risks and benefits of participation
- Participants verbal or written consent to participation.
- Documented consent of participants
- Minors and persons with diminished autonomy are entitled to additional protection – seek the guardian's consent.

CLM should ensure beneficence to participants. CLM should not harm participants. CLM should maximize possible benefits and minimize possible harm to participants. CLM should ensure data confidentiality and data security at all stages of the CLM data collection, analysis, and reporting to reduce harm to participants.

CLM should ensure justice. The burdens and benefits of CLM should be distributed fairly among individuals, groups, and societies participating in CLM. The CLM data should be analyzed and used to co-create solutions at the local levels such as health facilities.

Ensure collection of data in consideration of context sensitivity. Ensure safeguarding unauthorized data sharing and use of institutional information collected through CLM.

The CLM protocol shall be approved by the CLM coalition at national and sub-national levels.

6.5. CLM data quality

Ensuring the quality of CLM data is critical to the co-creation of solutions and advocacy. Poor quality data is a very serious threat to CLM. CLM data shall be fairly accurate to engage stakeholders and make evidence-informed decisions. Therefore, it is of utmost importance to ensure that the data being collected to support decision-making is of high quality. Data quality assurance and data quality audit shall be an integral part of CLM.

The CLM data quality assurance shall include:

- Using the correct data collection methods and tools. This might include the review and approval of CLM protocol and tools by the CLM coalition. Data collection tools and methods shall be field-tested and improved over time.
- Recruitment, training, deployment, and retention of the right data collectors and supervisors. Data collectors and supervisors shall have the competence or skills and attributes for the task, they shall be trained, supervised, and supported to collect good-quality data.
- Routine supervision and spot checks of data collectors to monitor data quality. There should be routine supervision and support of data collectors.
- Conduct a data quality audit to examine the CLM data for accuracy, completeness, and consistency. The data quality audit shall improve the quality of the data by spotting and filling gaps, identifying and fixing mistakes, and weeding out duplicate records.

6.6. CLM data entry, analysis, and reporting

- Data entry and analysis (database and analysis software) should be decided and prepared early by the implementers /host.
- Proper descriptive and analytical statistics used to calculate and compare indicators.

- Data entry, analysis, and reporting shall be done at the point of service delivery (health facility and community level) for rapid feedback and co-creation of solutions at each of the health facilities.
- Data aggregation, analysis, and reporting will be done at woreda, zonal, regional, and national levels by implementers and CLM hosts supported by the coalition.
- Data shall be analyzed, and findings presented to the CLM coalition within a month from completion of data collection at the health facility and, woreda level, and within three months at zonal, regional, and national levels.
- Data shall be presented and cleared by the CLM coalition at respective levels before public dissemination.

6.7. CLM data use and dissemination of findings

Findings from the analysis of CLM data for each health facility should be discussed with the respective health facility head and HIV focal, and the Woreda CLM coalition meeting and solutions should be co-created to improve access to and quality of services. The HIV focal persons at the health facilities and community programs shall develop a plan of action to improve the availability, quality, acceptability, and accessibility of HIV services based on the gaps identified through CLM.

The health facility head and HIV focal persons, and CLM team should follow up implementation of the solutions. The gaps that have no solution at the health facility and community services that need advocacy and action at the woreda, zonal, regional, and national levels should be identified and communicated to CLM hosts and implementers to conduct advocacy at woreda, zonal, regional, and national levels with the support of national, regional, zonal and woreda CLM coalitions.

Data aggregated and analyzed at the national, regional, zonal, and woreda levels should be presented to respective CLM coalitions before dissemination. The findings should be discussed to identify key gaps and co-create solutions with woreda and zonal health offices, RHBs, and MoH. The Host and implementing organizations should follow up with woreda and zonal health offices RHBs, and MoH for the implementation of solutions co-created.

The CLM coalitions, host, and implementing organizations will use a range of strategies for advocacy on persistent service and policy gaps including high-level meetings, policy briefs, media campaigns, social media campaigns, presentations in the National and Regional review platforms, etc.

6.8. CLM data ownership

The owners of CLM data should be the CSOs and community-led organizations hosting and implementing CLM.

7. Establishing CLM

Ethiopia CLM adopted the following five stages comprehensive conceptual framework for establishing community-led monitoring :

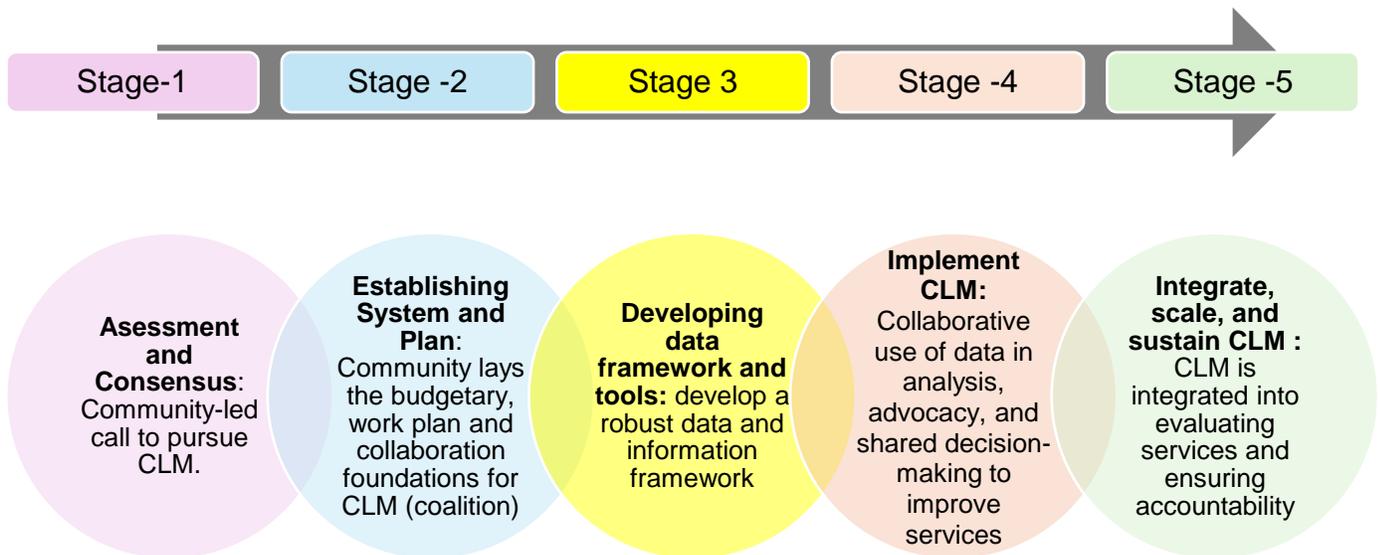


Figure 2 The Five stages of establishing community-led monitoring.

The key tasks/activities and outcomes of each of the five stages of establishing CLM is as follows:

Stage 1 community-led assessment and consensus on the implementation of CLM.

- Presentation of CLM concept, aims, and objectives to the full range of affected community members.
- Deliberative process that may include a formal or informal situational analysis of strengths, weaknesses, opportunities, and threats.
- Identify and describe CLM-related funds and other resources available or likely to become available. Finalize and confirm funding and other available resources.
- Engage with the Ministry of Health and regional health bureaus at the highest possible level for consensus.

Outcome: Consensus and Community-led call to pursue CLM

Stage 2: Establish the budgetary, work plan, and collaboration foundations for CLM.

- Establish the woreda, zonal, regional, and national CL coalition involving CLOs/CSOs, government, partners, academia, and donors - leadership by an existing CLO/CSO network.
- Agree on a host organization (CLO/CSO network) with leadership and collaborating roles and defined responsibilities.
- The CLM host organization develops a CLM work plan in collaboration with the CLM coalition.
- CLM host develops a clear budget and seeks consensus from community-led groups and funders.
- Host secure political commitment – sign a memorandum of understanding with MoH and RHBs.

Outcome: Agreed organization arrangement, budgets, and work plans recorded in a memorandum of understanding between community-led groups and the government that includes the flow of funds and a conflict resolution process

Stage 3: Develop a robust data and information framework, and tools, and train CLM monitors.

- CLM host and implementers as well as members of the CLM coalition reach out to community members to provide information and provide training on standards in health services, and the structural enablers and barriers to accessing them.
- Consultation and community-led identification of priority concerns for monitoring
- Design and test data collection tools in response to priorities identified, adapting those already validated, where possible.
- Establish data security at all stages of collection use and storage.
- Prepare a robust monitoring and evaluation system for CLM activities (supervision, review, tracking)
- Consent and entry to health facility: Discuss with facility managers how data are collected and used in service evaluation, and plan how to integrate CLM.
- Recruit and train peer monitors conducting CLM and introduce them to communities and facilities.

Outcome: A trained team of community members with confidence and competence in evidence-informed tools and secure data management systems that are ready to pilot CLM.

Stage 4: Community members collect, analyze, and use data for advocacy, and shared decision-making to improve services.

- Pilot the data collection, analysis, and advocacy workflow, and adapt as necessary.

- Move to routine data collection.
- Engage community and stakeholders: Share findings and develop advocacy messages.
- Solve problems and advocate for action: Present data in the service review and improvement process, propose and advocate for solutions, and agree on changes.

Outcome: CLM piloted and moved to routine data collection, analysis, and engagement for the co-creation of solutions and advocacy.

Stage 5: CLM integrated with the health service decision-making process, scaled and sustained.

- Monitor the commitments to change and any resulting innovation, looking for trends and impact.
- Integrate: Provide regular feedback to the community and the health facility/program
- Scale: Continue listening and acting on points of concern, enlarging the data collection strategy and themes, if necessary
- Sustain: Consolidate capacity, strengthen available expertise and funding to sustain CLM

Outcome: CLM integrated health facility feedback loop, engagement is maintained, CLM scaled and sustained to improve health.

8. CLM Implementation Arrangement

The following figure depicts CLM implementation arrangement in Ethiopia:

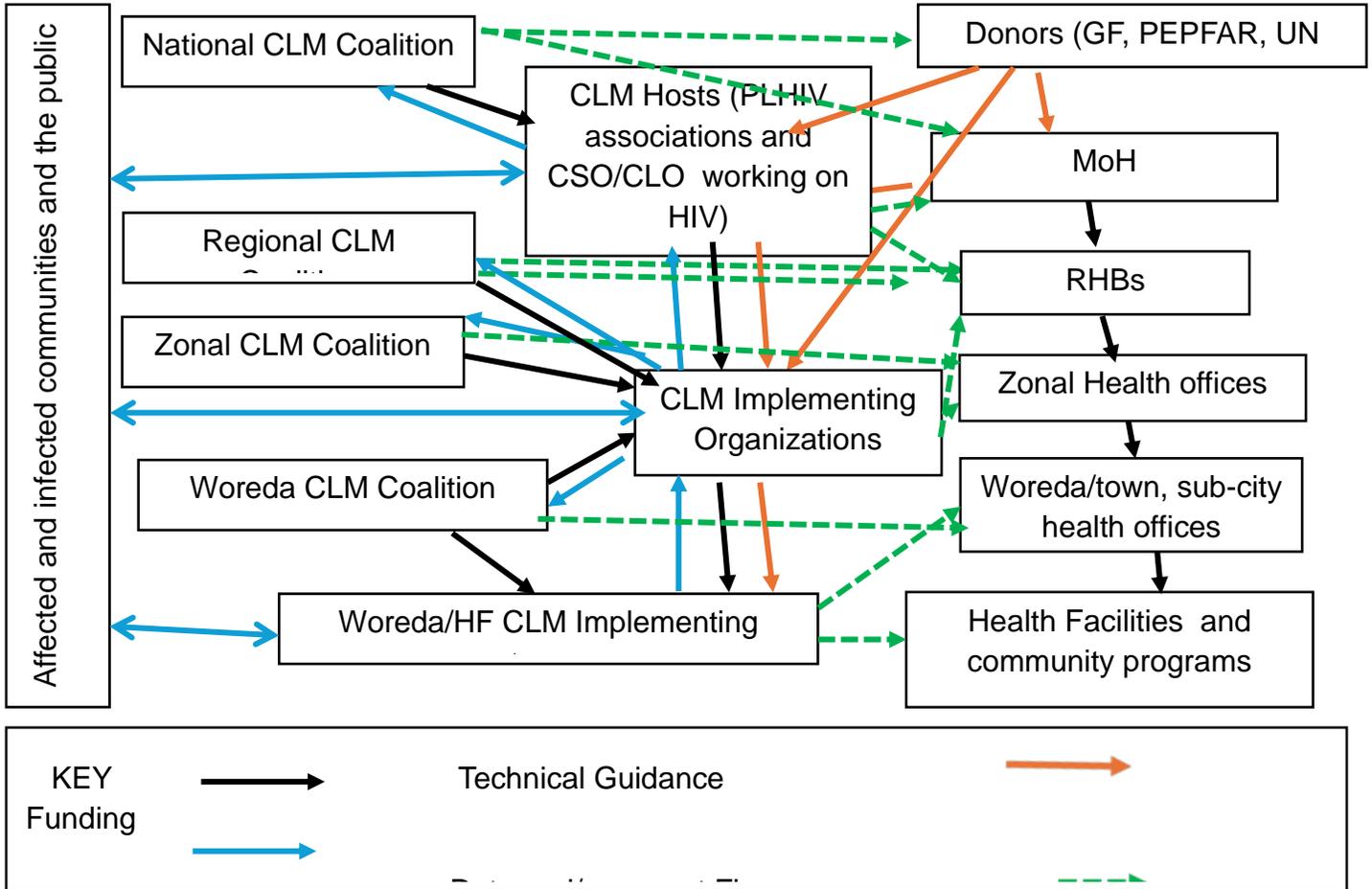


Figure 3 Ethiopia CLM Implementation arrangement.

National, Regional, Zonal and Woreda CLM Coalition

The CLM Coalition provides technical guidance in the design, implementation, and monitoring of CLM. The Coalition provides technical and advocacy support to the host and implementing organizations. CLM coalition will support host and implementing partners in the following tasks depending on its level:

- The development of CLM national framework
- Develop CLM data collection methods and tools
- Conduct data quality audit including reviewing and endorsing data.
- Analyze data, identify gaps and co-create solutions.
- Identifying advocacy agendas, developing an evidence-based advocacy plan, and implementing advocacy plan.
- Accessing national policy and political forums with the host organization to present and integrate data into health information policies and systems.
- Supporting the implementing partner to mobilize resources for sustaining CLM and related advocacy beyond the current grant funding.
- Monitoring CLM performance – Changes over time (impact)

National CLM Coalition will be composed of UNAIDS, MoH, EPHI, The Global Fund Country Coordination mechanism secretariat, WHO, PEPFAR, USAID, CDC, ,ASK US , NNAPWE, and CSOs, NGOs and partners working HIV and academic institutions, representatives of people affected and infected by HIV. The national CLM Coalition will select a secretary at its first meeting. The Coalition chair will be selected by the members but the Hosts are not allowed to chair the Coalition. The list of nominated organizations will be defined in the national CLM coalition terms of reference. The National CLM Coalition will be meeting monthly for the first 6 months and quarterly thereafter. The CLM Coalition Chair will lead the CLM meetings. The vice-chair will call CLM Coalition meetings on behalf of the CLM coalition and chair CLM meetings in the absence of the chair. CLM secretary will minute CLM meetings and act as secretary of CLM coalition.

Regional CLM Coalition will be composed of the CLM host or implementer, RHB, RHAPCO, UN, PEPFAR partners, CLM host and implementers, CSOs, NGOs and partners working HIV and academic institutions, representatives of people affected and infected by HIV. The regional CLM Coalition will select a secretary at its first meeting. The Coalition chair will be selected by the members but the Hosts are not allowed to chair the Coalition. The list of nominated organizations will be defined in the regional CLM coalition terms of reference. The regional CLM Coalition will be meeting monthly for the first 6 months and quarterly thereafter. The CLM Chair will lead the CLM meetings. The vice-chair will call CLM meetings on behalf of the CLM coalition and chair

CLM meetings in the absence of the chair. The CLM secretary will minute CLM meetings and act as secretary of the CLM coalition.

Zonal CLM Coalition will be composed of the CLM implementer (Chair), Zonal health office (vice chair), CSOs, NGOs and partners working HIV and academic institutions, representatives of people affected and infected by HIV. The zonal CLM Coalition will select a secretary in its first meeting. The list of nominated organizations will be defined in the zonal CLM coalition terms of reference. The zonal CLM Coalition will be meeting monthly for the first 6 months and quarterly thereafter. The CLM Chair will lead the CLM meetings. The vice-chair will call CLM meetings on behalf of the CLM coalition and chair CLM meetings in the absence of the chair. The CLM secretary will minute CLM meetings and act as secretary of the CLM coalition.

Woreda CLM Coalition will be composed of CLM implementing organization at the Woreda level (chair), Woreda health office (vice chair), Health facilities heads, and HIV service leads, CSOs, NGOs and partners working HIV and academic institutions, representatives of people affected and infected by HIV. The zonal CLM Coalition will select a secretary in its first meeting. The list of nominated organizations will be defined in the woreda CLM coalition terms of reference. The Woreda CLM Coalition will be meeting monthly for the first 6 months and quarterly thereafter. The CLM Chair will lead the CLM meetings. The vice-chair will call CLM meetings on behalf of the CLM coalition and chair CLM meetings in the absence of the chair. The CLM secretary will minute CLM meetings and act as secretary of the CLM coalition. The Woreda CLM Coalition plays a critical role in facilitating data collection, analysis, and using data to improve the quality of services at health facilities at the Woreda level.

CLM Host Organizations

The host organizations will be CSOs or CLO networks working on HIV at the national or regional level and selected by the CLM coalitions at the national or regional level. The CLM host must be a CSO/CLO network who can lead the design and implementation of CLM.

Building capacity and ensuring the quality of CLM will be effective and efficient when there are fewer host organizations and many implementing partners under the host organizations at grassroots level implementing CLM on a day-to-day basis.

The host organizations will be responsible for assessment and consensus creation, establishing the implementation arrangement and planning of CLM, and developing data framework and tools, data aggregation, analysis, reporting, and advocacy at national and sub-national levels. The host organization will develop the CLM protocol and train CLM staff and CLM coalition members. The Host organization will sign a MoU

with MoH and RHBs to facilitate the implementation of CLM. The Host organizations will have staffing for CLM that includes CLM coordinator and M&E officers.

CLM implementers

CLM implementers will be CSOs/CLOs working on HIV at national, regional, zonal or woreda levels who have the capacity to routinely and systematically collect, analyses and use CLM data to improve services. There will be many CSOs/CLOs implementing CLM close to sites to be monitored based on scope of CLM and available funding. The closer the CLM implementer to the sites monitored is the better. The CLM implementers will chair the CLM coalition at Zonal and woreda levels. The CLM implementer will have M&E officer/Supervisor and CLM monitors (data collectors) the following staff depending on the number of woredas covered. The CLM implementers will collect quantitative and qualitative data. The CLM implementers will monitor data quality. The CLM implementers will conduct analyses and report data at zonal, woreda, and health facility level. The CLM implementers will work with the health facility and community programs to co-create solutions for the gaps and barriers identified through CLM and monitor changes over time.

MoH, RHBs, Zonal, Woreda/town/sub-city health offices

MoH, RHBs, zonal and woreda/town/sub-city health offices will be responsible to

- Call CLM meetings on regular schedules and emergency meetings requested by the CLM chair.
- Chair CLM coalitions in the absence of the chair.
- Provide technical and political support to CLM host and implementers.
- Facilitate access to data at health facilities and program levels.
- Work with CLM hosts and implementers to co-create solutions to improve quality and access to services and protect human rights.
- Facilitate platforms to disseminate and advocate CLM findings including the annual and semi-annual review meetings.

Health facilities and data collection sites.

Data will be collected at public health facilities and community services (DICs). The CLM sites will be selected based on criteria such as woreda incidence (priority woreda), Client load, and facility performance gaps. Once sites are selected, a formalized partnership will be established between the host/implementing organization and the site via a memorandum of understanding (MoU). The health facility head and HIV services focal points will be members of Woreda CLM and provide technical support in data collection, analysis, reporting, and co-creation of solutions to improve services. Health Facilities will provide CLM implementers /data collectors access to health facilities and

facilitate quantitative and qualitative data collection. The Health Facilities heads and HIV focal will work with the CLM implementing team to discuss the CLM findings and co-create the solution to the identified service gaps. The health facility will implement solutions and monitor changes over time.

Donors and Partners

Donors and partners including academic institutions will provide technical and financial support to CLM host and implementers. The support of donors and development parents needs to focus on the realization of co-created solutions at the health center level. Donors will align their support to avoid duplication of efforts and create synergy – the division of support by geographic, population, or cost areas.

Affected community members.

Affected community members will provide data and implement CLM with the host and implementing organizations. They will use the CLM findings to act and advocate for their rights.

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