

Community-led monitoring in action



Emerging evidence and good practice

Cover: Angel Ntege, the CLM community monitor in Kikuube district, engaging with an expert client during CLM data collection at a Kabwoya Health Center. In this facility, the expert client, having lived positively for over 15 years, supports the clinic by addressing issues related to stigma and discrimination, conducting health talks, and encouraging people living with HIV to embrace positive living and adhere to their treatment for its benefits.

Photo credit: Adella Mbabazi/International Community of Women living with HIV Eastern Africa, Uganda.

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Foreword

Community-led monitoring (CLM) has gained momentum in recent years as a revitalized and reimagined intervention that mobilizes communities affected by health inequalities to monitor how services are provided and co-create solutions with key partners to improve them.

CLM as part of the community-led response is playing a significant role in bridging the “last mile” gaps by providing good-quality services to the right people, in the right ways, in the right places, thereby contributing to ending AIDS as a public health threat, addressing other health issues such as TB and malaria, and minimizing health inequalities.

This report aims to serve as a snapshot in time. It seeks to document the main lessons learnt in an accessible format. It supports national decision-makers to scale up discussions around the value and contribution of CLM to national AIDS responses and other health programmes.

As we face an historic opportunity to scale up CLM, UNAIDS is committed to working through strong partnerships to support countries in designing, conducting and sustaining CLM as part of broader community-led response work into the future. We invite you to join us.



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Abbreviations

AFSA	AIDS Foundation South Africa
AIDS	acquired immunodeficiency syndrome
CDC	United States Centers for Disease Control and Prevention
CLAW	Community-led Accountability Working Group
CLM	community-led monitoring
CNC	Community Network Consortium
COP	Country Operational Plan
COVID-19	coronavirus disease 2019
CTO	community treatment observatory
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV	human immunodeficiency virus
ITPC	International Treatment Preparedness Coalition
PEPFAR	United States President's Emergency Plan for AIDS Relief
PrEP	pre-exposure prophylaxis
RAS+	Réseau des Associations de Personnes Vivant avec le VIH au Togo
REAct	Rights–Evidence–Action
REBAP+	Réseau Béninois des Associations de Personnes Vivant avec le VIH
TAC	Treatment Action Campaign
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development

Introduction

Community-led monitoring (CLM) is a cyclical process in which people affected by health inequities,¹ particularly in HIV, tuberculosis (TB) and malaria, systematically monitor services, analyse the data they collect, and conduct evidence-driven advocacy to improve service delivery, generate solutions and create an enabling environment for their well-being. This is done in collaboration with key partners as part of the community-led response.

CLM has existed in different forms for decades, but it has been largely overlooked by global health actors. Now this is changing. CLM is gaining traction as an approach to improve the health of people from communities most affected by diseases such as HIV, TB and malaria.

Evidence shows that CLM improves the effectiveness, quality and accessibility of health programmes. CLM empowers communities affected by HIV, TB and malaria, strengthens community-based and community-led networks and organizations, and builds local leadership. CLM also enables people to demand high-quality services and fulfilment of their human rights, while contributing to a country's disease programmes and strengthening the health system.

To be responsive, CLM must be flexible, able to adapt to changing circumstances, and guided by principles of CLM and community-defined priorities.

Emerging evidence demonstrates that broader health systems benefit from embedding robust and flexible CLM models in their infrastructure. The experience of the COVID-19 pandemic shows that CLM can be deployed for new disease outbreaks if the communities most affected are in the lead. In some countries, CLM identified medicine stockouts even under mobility restrictions due to lockdowns. In other countries, COVID-19 accelerated the expansion of CLM from a vertical HIV approach to a multi-disease approach.

Beyond health systems, CLM produces other positive outcomes that form a ripple effect. CLM strengthens community networks and community-led organizations, builds relationships between grassroots organizations and government officials, and encourages service beneficiaries to speak up to receive better care. Ultimately, CLM empowers individuals and communities to engage with local government and power structures, which in turn cultivates a culture of participation, where citizens hold their representatives and other duty-bearers to account.

As health actors look towards CLM to improve the quality of health services and systems, it is necessary to review the current state of CLM, and to document opportunities for CLM to become an integral part of community-driven national responses.

¹ Health inequities are "differences in health status or in the distribution of health resources between different population groups, arising from the social conditions in which people are born, grow, live, work and age. Health inequities are unfair and could be reduced by the right mix of government policies" (1).

This report synthesizes the available information on the value of CLM in four key areas:

- HIV and health services.
- Creating an enabling environment.
- Community systems strengthening.
- Crafting better-defined policies and investments.

History of CLM

Modern CLM health interventions are built on an older lineage. Since the advent of global health efforts in the middle of the twentieth century, the concept of community-led and community-guided priorities and programmes has been integral to major development actors (2).

Principles of community engagement and leadership are upheld in numerous international declarations, including the 1978 Alma-Ata Declaration, the Sustainable Development Goals, the United Nations 2016 and 2021 political declarations on HIV, and the Joint United Nations Programme on HIV/AIDS (UNAIDS) Programme Coordinating Board resolutions. The history of modern social movements also reveals the power of communities taking matters into their own hands. This can contribute to the improvement of social accountability in delivering good-quality health services (2).

There is no definitive global history of CLM, but HIV experience shows that community organizations and networks pioneered forms of CLM with scant resources from the 1980s. From the earliest days of the AIDS epidemic, communities of people living with HIV came together to counsel, document and push governments to respond. In South Africa, the Treatment Action Campaign (TAC) combined facility monitoring with community mobilization to drive a policy and advocacy agenda. In Thailand, Uganda, Zimbabwe and other countries, communities united to link members to health care or to demand the creation of services.

By engaging communities to observe local health systems, identify problems as they occur, and seek appropriate remedies in concert with governments, what we call CLM today is the natural expansion of many of these principles and early programmes.

CLM continued to evolve into the twenty-first century. Sustained advocacy by civil society has increased international support for CLM, expanding the funding available and resulting in CLM interventions in diverse settings. Major international donors now support investments in CLM, building on years of smaller-scale funding by governments, foundations and private donors.

In 2020, in line with the demands of stakeholders, particularly civil society, the Government of the United States of America formally incorporated CLM into the United States President's Emergency Plan for AIDS Relief (PEPFAR) strategy, spending US\$ 20.8 million on community-based monitoring and CLM programmes in 2020 and US\$ 19.6 million in 2021 (3).

In its 2020–2022 allocation cycle, the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) invested approximately US\$ 36 million in CLM interventions across the three diseases and is poised to increase investments in its next funding cycle.

Scope and methodology

This report draws on a non-exhaustive literature review of published and unpublished materials provided by the UNAIDS Secretariat (including country offices) and partners. Most published literature on CLM concerns HIV, but this report also shares insights and lessons learnt applicable to other diseases and health contexts.

The report is not comprehensive or representative of all CLM interventions globally. Instead, it aims to inform and inspire stakeholders on the value of CLM based on the documentation of promising and established CLM programmes.

Evaluation of CLM work is an exception rather than the norm at the time of producing this report. It is important to note that many CLM programmes run on short donor-driven cycles and therefore do not have rigorous evaluations.

Most of the information is drawn from secondary data in monitoring reports rather than independently verified data. Much of the available literature on CLM projects focuses on Africa, and therefore those examples are most prominent in this report.

The report provides a snapshot of current progress and challenges in the field of CLM. It is intended to be used broadly, beyond the community of CLM practitioners, to stimulate discussions among stakeholders at different levels to better understand CLM. It offers suggestions for governments, community organizations, implementers, technical partners and donors that want to begin or expand CLM programmes in country settings.

The report has been reviewed by and received written comments from over 20 organizations and individuals working on CLM around the world.

Defining community

There is no internationally agreed definition of community. The World Health Organization defines communities as “groups of people that may or may not be spatially connected, but who share common interests, concerns or identities” (4).

A community in the context of CLM typically refers to people living with or affected by a disease, which may include people living with HIV, TB or malaria; people from key populations; or people from other groups marginalized due to age, gender identity, sexual orientation, occupation, ethnicity, race or other factors.

A community may also refer to a group of people who use health services, or people in a specific geographical location. Community-led organizations are led by the people they serve and are primarily accountable to those people. According to UNAIDS, this includes “organizations by and for people living with HIV or tuberculosis and organizations by and for people affected by HIV, including gay men and other men who have sex with men, people who use drugs, prisoners, sex workers, transgender people, women and young people” (5).

Essentials of CLM

“COMMUNITY-LED MONITORING HIGHLIGHTS ISSUES AND BRINGS THEM TO THOSE WHO CAN ACT UPON THEM; IT IS A SYSTEMATIC AND CONTINUOUS PROCESS THAT SEEKS TO BRING ABOUT SUSTAINABLE CHANGE” (6).

Definitions

There is no universally agreed definition of CLM. There is a shared core concept, however, and all definitions have the following common elements:

- CLM is an ongoing process in which people accessing health care or in a community and affected by health inequities systematically monitor services.
- Communities analyse the data they collect and conduct evidence-driven advocacy.
- Communities monitor the wider environment affecting health, such as documenting human rights violations, and raise issues with the relevant authorities.

Disease-specific and general definitions for CLM exist. This report focuses on the UNAIDS definition. Others definitions are included in Annex 1. The UNAIDS definition includes the following:

- CLM is an accountability mechanism for HIV responses at different levels, led and implemented by local community-led organizations of people living with HIV, networks of people from key populations, other affected groups or other community entities.
- CLM uses a structured platform and rigorously trained peer monitors to systematically and routinely collect and analyse qualitative and quantitative data on HIV service delivery—including data from people in community settings who might not be accessing health care—and to establish rapid feedback loops with programme managers and health decision-makers.
- CLM builds evidence on what works well, what is not working and what needs to be improved, with suggestions for targeted actions to improve outcomes.

Core principles

In August 2022, a joint position statement from technical assistance providers, which represents civil society organizations working on CLM, articulated the following core principles of CLM:²

- CLM is independent from donors and from national governments.
- CLM is built by communities, from identifying priority indicators to preparing questions and defining preferred channels of communications, from monitoring to owning and housing the data.
- CLM is led by directly impacted communities, such as people living with HIV, TB or malaria and people from key populations.
- CLM includes advocacy activities with the aim of generating political will, while focusing on advancing equity and accountability.

² Signatories: Advocacy Core Team (Zimbabwe), amFAR (United States/global), APCASO (Asia-Pacific region), Asia Pacific Coalition on Men's Sexual Health (Asia-Pacific region), ATAC (Ukraine), Caribbean Vulnerable Communities Coalition (Caribbean region), Civil Society for Malaria Elimination, Eastern Africa National Networks of AIDS and Health Service Organizations (United Republic of Tanzania), Eurasian Coalition on Health, Rights, Gender and Sexual Diversity (eastern Europe and central Asia region), Global Coalition of TB Advocates, Health GAP (United States/global), Impact Santé Afrique, International Treatment Preparedness Coalition (ITPC) EECA (eastern Europe and central Asia region), ITPC Global (South Africa/global), ITPC West Africa (western and central Africa), MPact Global Action for Gay Men's Health and Rights, O'Neill Institute for National and Global Health Law (United States/global), TAC (South Africa/global).

- CLM adheres to ethical data collection, consent, confidentiality and data security. Data collection must be verifiable, reliable, conducted in a routine or continuous cycle, and collected under “do no harm” principles.
- CLM data are owned by communities and programmes are empowered to share CLM data publicly. CLM programmes should not re-gather or duplicate monitoring and evaluation data from existing systems.
- CLM monitors are representatives of service users, and are trained, supported and paid adequately for their labour, while maintaining community independence from donors.
- CLM is coordinated by a central, community-owned structure capable of managing the effort.

Community-based monitoring

Some organizations, such as the Global Fund, previously used the term community-based monitoring, which was broader in scope and referred to civil society organization-led monitoring. Now there is wide consensus of using the term CLM, including by the Global Fund in its 2023–2028 strategy and operational documents.

Process

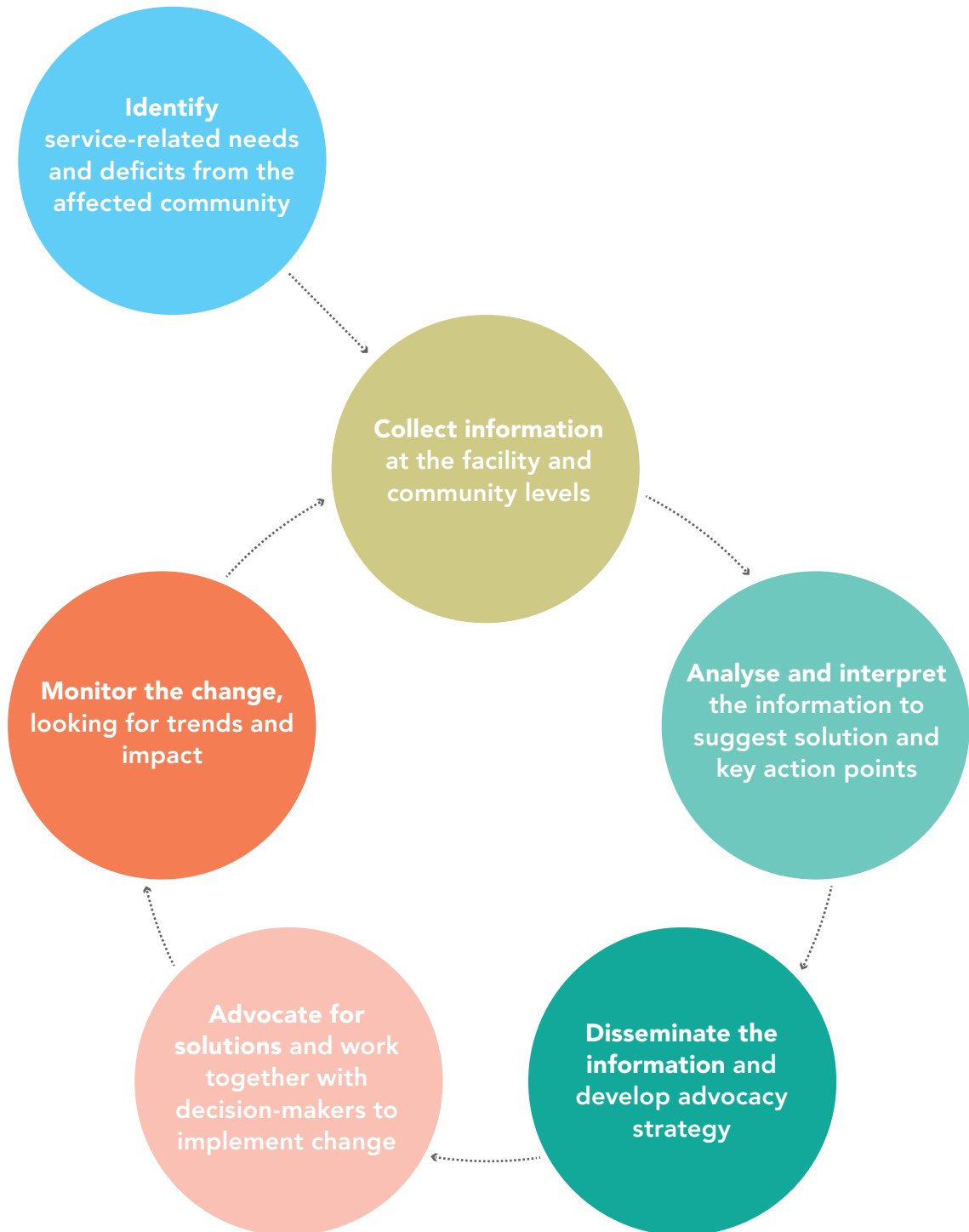
Several existing resources outline how to develop a CLM programme or pilot (7–15). The process of creating a CLM programme generally includes the following (15):

- A community-led call to pursue a CLM pilot or programme.
- A community-led process in which the community outlines core programme parameters, including a workplan, budget and governance, based on a quick community assessment of their rights, service needs and gaps.
- A community-led process to create a data collection and analysis framework and advocacy plans, ideally to be embedded in existing feedback loops and decision-making mechanisms.

When designing or running a CLM programme or pilot, it is helpful to keep in mind the CLM cycle as a reminder that CLM, as part of community-led responses, is a process and not a one-off activity. The key steps in the cycle are (Figure 1):

1. Identify the needs of the affected community.
2. Collect information at the facility and community levels.
3. Analyse and interpret the information to suggest key action points and solutions.
4. Disseminate the information to key stakeholders (e.g. clients, facility managers, government representatives) and co-create solutions with them.
5. Monitor any changes for affected communities.

Figure 1.
Integration of CLM into service review and improvement



Source: Adapted from O’Neil Institute, Treatment Action Campaign, Health Gap, ITPC, ICW, Sexual Minorities Uganda (SMUG) et al. Community-led monitoring of health services: building accountability for HIV service quality (https://healthgap.org/wp-content/uploads/2020/02/Community-Led-Monitoring-of_Health-Services.pdf)

Value of CLM

Improving health services and building more resilient health systems

Access to services

CLM identifies problems that people have faced in accessing health services in previous years. Access can be constrained by many factors, such as limited clinic opening hours, the distance of a clinic from home, stigma and discrimination towards people from key populations, and out-of-pocket expenditure. Health programmers may not be aware of the difficulties people from certain groups face in seeking care.

In Malawi, the Pakachere Institute of Health and Development based in Lilongwe discovered through CLM that female sex workers were denied care at clinics if they could not present their passports. Based on this information, the Ministry of Health removed the passport requirement, allowing sex workers to receive care at any clinic in the country without identification (16).

Affordability

Direct and indirect fees to access health services affect millions of people. In a number of countries, CLM has resulted in the abolition of user fees for HIV-related services, a major barrier to uptake of services.

In Côte d'Ivoire, CLM data showed that user fees prevented people living with HIV from accessing antiretroviral therapy, even if the medicines were free, because they could not afford to pay for doctors' visits, treatment for minor infections or diagnostic tests. After the CLM implementer Réseau Ivoirien des Organisations de Personnes Vivant avec le VIH/SIDA (RIP+) shared its findings with the Ministry of Health and PEPFAR, the Government issued guidance that all HIV testing and treatment services in the country must be free of charge (17).

CLM data contribute to better health systems and improved health outcomes

In the Democratic Republic of the Congo, a CLM observatory on the quality of care for HIV and TB contributed to a drastic reduction in medicine stockouts, from 95% at the beginning of 2019 to 5% in December 2019 (6).

In Nigeria, CLM data collected from 1998 facilities across 172 local government areas have been used by state governments to renovate health facilities, redeploy and replace health staff, address malaria commodity stockouts, and train facility staff in improved data entry to avoid future stockouts. CLM data have also been used by facility managers to curtail staff absenteeism, improve staffing hours and improve staff attitudes towards clients (18).

In South Africa, 35% of people living with HIV reported 3-month antiretroviral refills in 2022 compared with only 18% in the same reporting period for 2021 (19).

In Uganda, the use of citizen report cards to track the quality of health services contributed to higher child immunization rates, decreased mortality rates among children aged under 5 years, reduced absenteeism of health-care providers, and shorter waiting lines at clinics (4).

Availability of services, medicines and essential tools

Health services, medicines, diagnostic devices and other equipment are essential to preventing, diagnosing and treating diseases. CLM swiftly identifies when medicines or other tools are missing so that governments can quickly remedy problems. In multiple countries, CLM has identified stockouts of essential medicines, improved supply chains, and increased access to medicines for people living with HIV and TB.

In a hospital in Benin, CLM implementer Réseau Béninois des Associations de Personnes Vivant avec le VIH (REBAP+) identified that laboratory reagents had been missing for over 10 months. As a result, people living with HIV had not received viral load or CD4 tests. After REBAP+ shared this information with the National AIDS Control Program, the Government supplied the hospital with reagents (17).

In Gulu province in Uganda, CLM documented a shortage of medicines for treating sexually transmitted infections. As a result, the National Drug Authority increased supplies in health facilities (20).

Building demand and uptake

In west Africa, a CLM project technically supported by ITPC that spanned 11 countries proved successful in building the demand of people from key populations for HIV treatment. At 16 health facilities, the number of new treatment initiations among gay men and other men who have sex with men, sex workers, and people who inject drugs rose from 63 in the first 6 months of the project to 420 and 1106 in the second and third 6-month periods (21).

In Zambia, the Centre for Infectious Disease Research implemented a CLM pilot supported by PEPFAR to improve viral load testing coverage. After 4 months of CLM, viral load suppression increased from 88% to 98% (12).

Empowerment and education of clients

CLM increases awareness about the value of empowering and educating clients. Treatment literacy programmes are critical to sustaining people on HIV treatment and retaining them in care.

In South Africa, CLM data reflected that 88% of people living with HIV said that a health-care provider had explained the results of the viral load test results in 2022 compared with 77% in the same reporting period in 2021—a key indicator of health and whether HIV can be transmitted onwards. As a result, there was a 2% increase in the proportion of people living with HIV who knew that an undetectable viral load means a person is not infectious, thanks to the CLM work done by Ritshidze (22).

Quality of services

The quality of health services has an impact on whether clients return for follow-up sessions and care. CLM data identify problems with service quality and offer suggestions for improvement.

In South Africa, several years of continuing CLM through the Ritshidze project have produced rankings of the five best- and worst-performing clinics based on criteria such as waiting times, safety, adequate numbers of staff and attitudes of staff. This allows Ritshidze to track the quality of services and identify where best practices in top-ranking clinics can inform other clinics to improve (22). CLM also draws attention to gaps in quality for specific groups of people.

Ritshidze CLM data identified the following human rights violations to accessing health services reported by people from key populations in South Africa:

- Some people who use drugs were denied access to care due to stigma.
- When some people from key populations arrived at clinics, staff shouted warnings to other clients to protect their belongings—a clear indication of discrimination.
- Some LGBTIQ people were humiliated during medical consultations when other health-care workers were brought in to look at or mock them.

Correctional actions have been taken and regularly monitored, with progress at different degrees documented in People's COP reports.

Rapid response to new epidemics

During the COVID-19 pandemic, a number of countries used CLM to understand how health services were affected. People living with HIV and other diseases faced restrictions on mobility due to lockdowns, contracting COVID-19, loss of income and other challenges.

In India, four community-based organizations in the state of Mizoram surveyed the needs of people living with HIV during COVID-19 and shared the data with the local government. As a result, the community-based organizations developed a collaborative relationship with the local government (23).

In Togo, Réseau des Associations de Personnes Vivant avec le VIH au Togo (RAS+) collaborated with the UNAIDS Country Office on a COVID-19 rapid assessment and surveyed 563 people in the Kara and Lomé regions. The analysis identified the following:

- There was a decrease in attendance at clinics due to fears of contracting COVID-19.
- The pandemic led to stockouts of antiretroviral medicines and had socioeconomic impacts on people living with HIV, including loss of employment and decreases in income.
- Five per cent of respondents reported experiencing physical or psychological violence.

This analysis was presented to the National AIDS and STI Control Program and other national stakeholders, and the country implemented the following changes:

- Scale-up of multimonth dispensing of antiretroviral medicines.
- Mobilization of districts and communities for joining government-led campaigns.
- Review of antiretroviral medicine delivery dates.
- Social protection measures.

In Uganda, CLM data during COVID-19 revealed gaps in awareness of HIV services by clients. For example, 57% of clients reported they were not aware of the presence of a support club at the facility or within the community. Knowledge of where to obtain and how to use pre-exposure prophylaxis (PrEP) was lacking among the clients surveyed.

The Bring Back to Care campaign was launched to address these gaps in the clinical cascade, along with peer online support programming to ensure continuity for clients unable or unwilling to attend in-person meetings.

Donors, the Ministry of Health and civil society organizations are working together to develop effective PrEP education, demand creation, and treatment literacy campaign materials. These efforts are valuable to improve prevention interventions and reduce interruption in treatment, especially as COVID-19 continues to impact on care seeking and delivery of HIV services.

CLM was deployed in at least one country to assess how the COVID-19 pandemic was affecting the food and economic security of pregnant women and children living with HIV and their caregivers. The data, which showed worsening food insecurity and precarious financial situations, were shared with policy-makers, who increased investments in emergency COVID-19 assistance (16).

ITPC community treatment observatory model in west Africa

The community treatment observatory (CTO) is a CLM model that systematically collects quantitative data across the HIV prevention, care and treatment cascade (21). Implemented by national networks of people living with HIV in partnership with ITPC Global, CTOs in 11 west African countries resulted in improved health systems and services, including:

- Reduced incidence of stockouts of medicines and laboratory reagents.
- Increased uptake of differentiated antiretroviral therapy service delivery models.
- Improved HIV treatment monitoring.
- Increased rates of HIV testing among people from key populations and young people.
- Shorter waiting times at facilities.
- Replacement of malfunctioning equipment.

Case study: Togo

Under the ITPC West Africa CTO model, Togo began a nationwide CLM programme in 2017. Led by RAS+, CTO began collecting data from 11 health facilities.

During the COVID-19 pandemic, CLM was expanded to 15 additional sites, and new diseases were included. Sixteen data collectors in 30 sites now collect information on HIV, COVID-19, malaria and TB.

Results

- At CTO-monitored health facilities from 2018 to 2019, the number of eligible people provided with post-exposure prophylaxis doubled, and the number of people from key populations (gay men and other men who have sex with men and sex workers) initiated on antiretroviral therapy increased 18-fold (21).
 - In 2019, CLM data revealed that some pregnant women living with HIV who were on antiretroviral therapy were being tested for HIV at a hospital in Lomé. As a result, these unnecessary HIV tests were halted, helping conserve supplies and ensure there were no recorded stockouts of HIV tests (24).
 - The CLM data generated around gaps in viral load testing are expected to contribute to the national HIV programme reviewing its budgetary allocations in this area and improving the availability of reagents (25).
 - Members from civil society organizations were integrated into the Viral Load Technical Committee.
 - In 2021, data from CLM during COVID-19 fed into a UNAIDS report on the situation and needs of people living with HIV in the context of COVID-19 (26).
 - The shift in Togo's CLM intervention from an HIV-specific to a multi-disease approach opened the door to new partnerships with the national TB and malaria control programmes.
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Enabling factors

- Health facility staff viewed the CTO data as credible and used the data in their work.
 - CTO used CLM data to make evidence-informed interventions at Global Fund Country Coordinating Mechanism meetings, which strengthened visibility and helped attract future funding.
 - Multipronged advocacy with different stakeholders was used to find a solution to viral load stockouts.
-

Improving health services and building more resilient health systems: key messages

- CLM can identify and resolve specific local barriers to service access that prevent communities from receiving care, such as identification requirements, clinic waiting times, and unnecessary travel to health-care sites.
- CLM can indicate swiftly when there are disruptions to the supply chain of essential medicines, diagnostics and other health tools, helping to restore the supply chain, save lives and prevent devastating health consequences.
- CLM can mitigate financial barriers that prevent people from marginalized communities from accessing health services.
- CLM can improve the quality of disease-specific and general health services, and help to integrate vertical, disease-specific approaches into horizontal systems.
- CLM can sharpen health policies and strategies to be more effective, cost-efficient and community-friendly through approaches such as differentiated service delivery.

Strengthening community systems

Improving networking and partnerships between beneficiaries, community actors and facilities for referral

CLM is a process that often produces unanticipated positive changes, helping to connect gaps in the health-care system.

In Ghana, a CLM intervention supported by ITPC conducted focus group discussions with people from key populations and was used as an opportunity to refer participants to key population-friendly health centres. During interviews and focus groups with health-care workers, the team included education on the importance of providing key population-friendly health services (21).

In Malawi, CLM documented a gap in programming for survivors of sexual and gender-based violence who received medical care at clinics but were not referred for psychosocial support. After this was raised in health-care management discussion forums, clinics appointed focal points to systematically support survivors to access mental health care (16).

In Uganda, CLM has created a culture of accountability between the community and facilities. Through inclusive CLM Coalition meetings, the status of CLM implementation and its findings are presented. The meetings also help all stakeholders to understand HIV and TB services and challenges and help to co-create and own solutions. At the same time, feedback on service delivery challenges that require immediate action and are within the mandate of the facility in charge are shared (20).

Expanding community engagement in national responses

CLM provides a direct way for civil society to become involved in decision-making and planning for health. This can include national strategies, grant applications and budget processes.

In Sierra Leone, the Global Fund supports the Civil Society Movement Against Tuberculosis to implement a nationwide CLM mechanism in the country's 16 districts and in more than 170 individual TB facilities. As a result, there is now stronger partnership and collaboration between the TB community and the public sector. Communities, community-based organizations and civil society are also more meaningfully engaged in Global Fund grant implementation (12).

In South Africa, after years of CLM implementation, Ritshidze became a member of Operation Phuthuma, the National Department of Health countrywide treatment acceleration plan. The Ritshidze project provides regular updates on its CLM findings to provincial and national health teams.

ITPC West Africa supported REBAP+ (Benin), Réseau des Organisations des Populations Clés de Côte d'Ivoire (Côte d'Ivoire), the Network of HIV Positives (Sierra Leone) and World Production (Democratic Republic of the Congo) to increase communities' capacity to engage meaningfully by supporting consultations with 1059 community members to highlight issues that need to be monitored through CLM. This basis was used to co-design monitoring indicators in these four countries.

Building capacity of communities

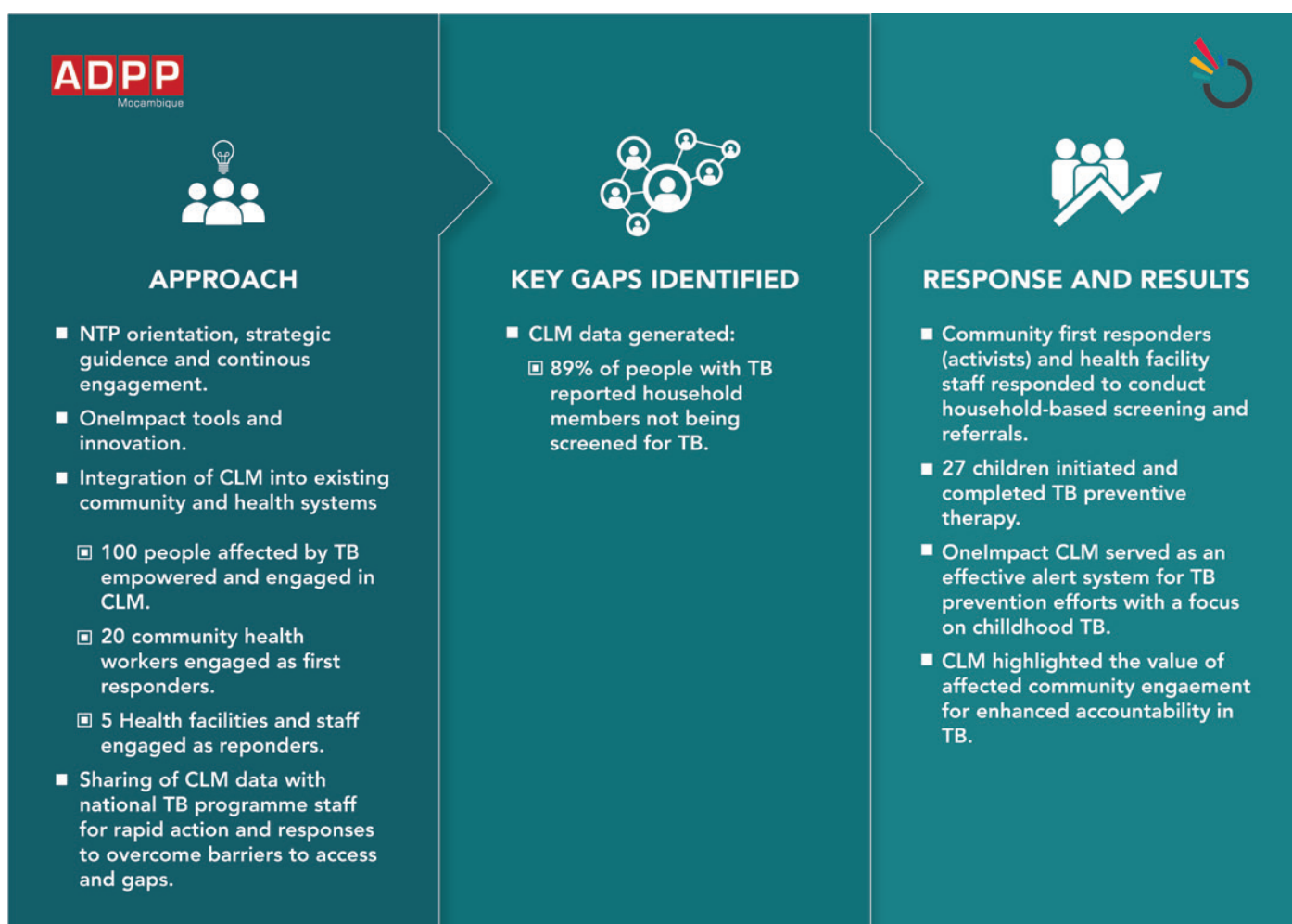
The CLM process builds capacity of communities that facilitate activities. For people from key populations and other affected groups, participating in data collection, analysis and advocacy develops skills in leadership, research, communication and social change. Because CLM supports communities and networks to engage with key decision-makers and influencers to sustain advocacy efforts, it also gives them increased visibility in the national response.

In Lubumbashi in the Democratic Republic of the Congo, capacity-building of community actors around multi-disease CLM approaches undertaken by World Production, with support from ITPC West Africa allowed CIELS, Réseau National des ONG pour le Développement de la Femme and UCOP+ to intensify their TB and malaria sensitization campaigns as part of routine HIV activities (25).

Case study: facilitating access to TB preventive therapy for children in Mozambique

Through the Stop TB Partnership OnelImpact CLM, people affected by TB are highlighting the challenges preventing people from vulnerable and marginalized populations accessing TB care and support services for rapid and sustained health and community system responses, and to reach missing people with TB. OnelImpact CLM ensures good-quality TB care and support services are available, accessible and acceptable for all. Figure 2 shows the results of CLM work carried out by ADPP in five facilities in Maputo province in Mozambique in 2019 and 2020.

Figure 2.
Results of CLM among people living with TB in Maputo, Mozambique



Strengthening community systems: key messages

- CLM strengthens health and psychosocial referral systems and networks, increasing the number of individual referrals, particularly for the people most affected by a disease.
- CLM increases the involvement of communities and civil society in national health planning processes, including funding proposals, budgets and implementation plans.
- CLM creates concrete partnerships and collaborations between communities and the national health sector.
- CLM empowers community-led organizations.

Creating an enabling environment

Promoting human rights

CLM documents human rights violations that prevent people from some communities from accessing prevention, treatment and care.

In 22 countries that hosted the Rights–Evidence–Action (REAct) intervention designed by Frontline AIDS and national partners, communities have documented over 16 000 cases of human rights violations since 2019 and brought them to the attention of national decision-makers.

In South Africa, the AIDS Foundation South Africa (AFSA) documented several cases of forced sterilization of women living with HIV in Limpopo province. In partnership with the Pro Bono National Institute, AFSA instituted strategic litigation to address this.

In Ukraine, analysis of the Alliance for Public Health REAct data showed many cases of police interfering with people on opioid substitution therapy. The data were used to develop recommendations, and legislation was put in place to issue special identification cards for opioid substitution therapy clients to use along with photo identification and health-care facility stamps in the case of police checks.

In Kyrgyzstan, the nongovernmental organization TB People conducts regular CLM of TB services including reporting on cases of human rights violations. As a result, the Ministry of Health created “trust councils” (public oversight boards established by the Ministry of Health where all issues and challenges are discussed and all board members are civil society representatives) at TB clinics that now use CLM data to improve services (27).

Removing social and legal barriers

CLM highlights structural challenges to accessing health services across the country. CLM can result in the removal of policy, regulatory and legal frameworks that are discriminatory against people from key populations.

In Kenya, advocates used CLM to collect evidence on barriers to accessing health services. They successfully referred 757 cases for legal support to a network of pro bono lawyers or the HIV Tribunal (16).

Expanding social protection

An emerging area of CLM seeks to identify when vulnerable people need social protection measures. CLM conducted during the COVID-19 pandemic was able to identify when people affected by HIV needed food or economic security aid.

In Togo, CLM led to the development of social protection measures, including an emergency plan of US\$ 695 million to support the poorest households as part of the National Solidarity and Economic Recovery Fund (21).

Creating an enabling environment: key messages

- CLM documents human rights violations and raises them with national decision-makers, contributing to changes to laws and policies.
- CLM removes social and legal barriers to care for people from key and marginalized populations.
- CLM identifies the links between health and social protection policies, illuminating how social protection programmes and policies can support the right to health, and vice versa.

Sharpening policies and investments

“Most health workers admitted to being unaware that many key population groups had been excluded. They realized these gaps are deeply rooted within national health programming and policy that make services, commodities and budgets available to certain categories only” (20).

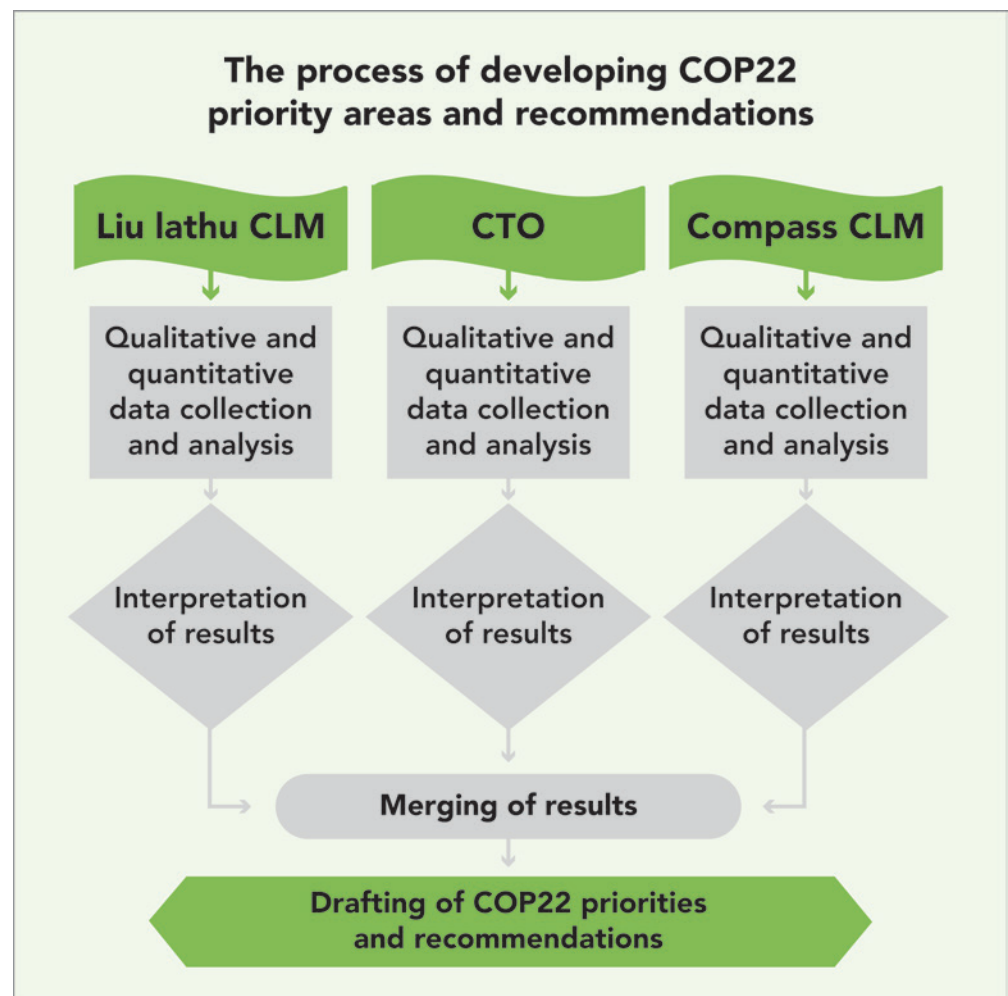
Health financing

CLM data can be used to inform and craft more cost-effective country budgets and plans.

In Namibia, CLM data informed the PEPFAR Country Operational Plan (COP), a package of PEPFAR country planning tools and the United Nations Population Fund family planning commodities quantification and forecasting process (23).

Several CLM implementers, including in Haiti, Kenya, Malawi, Mozambique, South Africa, Uganda and Zimbabwe, participated in the People's COP (28), feeding community perspectives into PEPFAR programming and budgets. Figure 3 shows how CLM projects fed directly into the People's COP in Malawi.

Figure 3.
Use of CLM findings in
COP22 process



CLM has led to increased budget allocations to laboratory services, staffing, medicines and supplies.

In the Democratic Republic of the Congo, as a direct result of CLM advocacy, the Clinton Health Access Initiative gave four new GeneXpert systems for viral load analysis to the national HIV programme laboratory of Haut-Katanga in December 2020. These will reduce the turnaround time of viral load test results in the zones covered by Lubumbashi's general referral hospital and other hospitals.

The CLM data generated around gaps in treatment for opportunistic infections have contributed to the national HIV programme and the Lubumbashi Essential Medicine Purchasing Center reviewing the availability of cotrimoxazole in health facilities. This has led technical and financial partners (the United States Agency for International Development (USAID) Integrated HIV/AIDS Project and the Centers for Disease Control and Prevention/ICAP) to plan the integration of cotrimoxazole purchasing into their programme packages for the fiscal year (25).

In Kazakhstan, the Kazakhstan Union of People Living with HIV conducted an analysis of public procurements of social services and state grants aimed at people who inject drugs and people living with HIV. They used the data to advocate for state funding for harm reduction services (29).

Evidence-based policy

CLM has contributed to the development of health strategies, policies and country-level guidelines. It also reveals flaws in existing policies

Case study: South Africa

Ritshidze is a CLM initiative monitoring the quality of HIV and TB services in some of the higher-burden public health facilities in South Africa. Ritshidze, co-led by five organizations of people living with HIV, means "save our lives" in the TshiVenda language (22). Over 4 years, Ritshidze has monitored 400 clinics and community health-care centres across 27 districts, covering nearly half of the people living with HIV who are on treatment.

Data collected since the project started have come from surveys of facility managers, patients, people living with HIV and facility-specific monitoring reports. In addition, CLM has gathered non-facility qualitative data from 80 sites, with 8 case studies, 65 testimonials, 50 videos and 8 films.

Process

- An open data dashboard (<https://ritshidze.org.za/>) allows easy tracking and visualization of clinic data. A rapid remediation report platform in the dashboard flags time-sensitive challenges.
 - Ritshidze gives monthly presentations on CLM results to Operation Phuthuma (National Department of Health-led working team for implementing the national treatment acceleration plan) to review progress and challenges, and to conduct follow-up activities in project sites.
 - Ritshidze monitoring teams conduct clinic review meetings to share data analysis and gaps identified.
 - Ritshidze has given three standalone advocacy-specific presentations to a broad range of audiences, including from the government, donors and technical support agencies, on issues identified, including staff shortages, vacancies, waiting times, filing systems, antiretroviral medicine refill length, multimonth dispensing, repeat prescription collection strategies, antiretroviral therapy continuity, transfer letters, treatment and literacy, psychosocial support, index testing, and stockouts and shortages of medicines.
-

Results

- Strong, well-organized community—five separate groups of people living with HIV united to form Ritshidze (National Association of People Living with HIV/AIDS, Positive Action Campaign, Positive Women’s Network, South African Network of Religious Leadership Living with or Affected by HIV and AIDS, and TAC).
 - Strong relationships with the Ministry of Health and PEPFAR.
 - Considerate policies for data collectors and other staff, including providing employees with access to professional counsellors and therapists free of charge.
 - Exchange and learning opportunities with international CLM colleagues, hosting teams from Mozambique and Zimbabwe and conducting training for CLM teams from Cameroon and Liberia.
-

Data insights

- Stigma and discrimination against people from key populations were a barrier to service access—people from key populations reported receiving inhumane treatment during medical consultations.
- Drop-in centres for people from key populations exist, but most people from key populations need to access regular clinics changes must be made to ensure access.

Figure 4. Ritshidze findings: where people from key populations access services in South Africa



WHERE	MSM	PWUD	SEX WORKERS	TRANS PEOPLE
Public health facility	86% [856]	85% [1.270]	76% [805]	75% [409]
Drop-in centre	6% [64]	10% [53]	2% [29]	2% [23]
Mobile clinic	8% [83]	12% [65]	7% [101]	21% [222]
Private doctor	7% [72]	10% [57]	8% [117]	5% [56]

Key messages

“Before Ritshidze, people would go to the clinic and would wait for the whole day—and there was no way to address it, no one would do anything to fix it. We were individuals complaining, and easily dismissed,” said Sibongile Tshabalala, Chairperson of the Treatment Action Campaign (TAC). “Ritshidze has empowered us to identify these systemic problems, bring the data to duty-bearers, and present solutions while holding them accountable to the community for making the necessary changes” (30).



Beatty Clinic, May 2022.
Credit: Rian Horn/Ritshidze



Kgotsong (Bothaville) Clinic, July 2022.
Credit: Rian Horn/Ritshidze

Good practice

A CLM DATA COLLECTOR FROM THE DEMOCRATIC REPUBLIC OF THE CONGO SAID: “WE LEARNT THROUGH THE CTO MODEL HOW PEOPLE LIVING WITH HIV CAN BE INVOLVED AND ENGAGED WITH EVIDENCE FROM THE GROUND.”

Over the past few years, different organizations have started to document CLM good practice. As CLM is highly context-specific, the following suggestions depend on the existing landscape and local dynamics. These practices are consolidated from referenced publications and the progress reports of CLM activities submitted to UNAIDS country offices.

Beginning CLM

Consider a baseline assessment

It is important to lay the groundwork for a successful CLM programme by understanding the context and setting, including which health services are offered for the affected community and current community concerns. Assessments can identify which organizations are best placed for implementing CLM, identify any regulations or administrative hurdles (e.g. whether non-patient-linked data collection requires approval from national ethics boards), and plan for technical assistance needs to avoid delays.

In the Democratic Republic of Congo, a baseline assessment in October 2020 by the Lubumbashi School of Public Health captured the HIV cascade of services in the city of Lubumbashi. It identified the needs of people from key populations in terms of HIV treatment access to inform the establishment of a CLM programme. A mixed-methods approach was used to collect data through 57 interviews and 4 focus group discussions in 9 sites representing more than 58% of the people receiving HIV care in Lubumbashi.

Assessments can:

- Identify all current or previous CLM efforts.
- Map the services that require monitoring.
- Identify the current needs of affected communities.
- Identify whether government approval is needed for data collection.

Bring together key stakeholders and authorities

When a CLM programme takes the time to unify key CLM stakeholders from the start, it ensures partners and government officials see the positive value of CLM. This increases the space for advocacy and develops helpful relationships between communities and health officials.

It is important to:

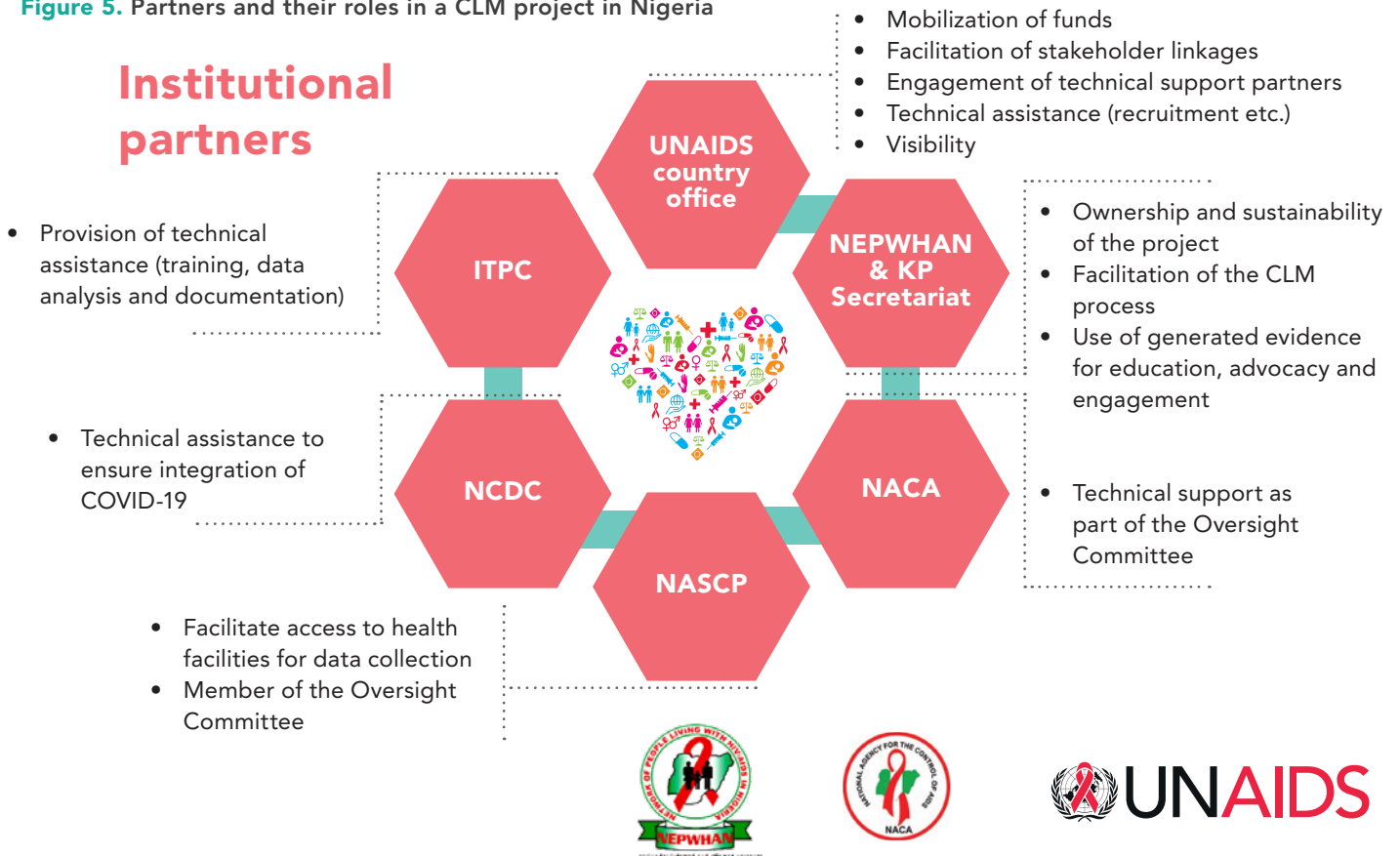
- Ensure communities are leading.
- Establish clear roles and responsibilities for each stakeholder, particularly the government, community groups conducting CLM, donors and technical support agencies.
- Create a sense of shared commitment around using CLM data to improve programmes.
- Create an enabling environment for CLM to work.

In Nepal, a national CLM task team was formed at the project's inception to strengthen coordination, technical guidance, oversight, networking and partnerships. The CLM task team comprises AHF Nepal, EpiC Nepal, the National Centre for AIDS and STD Control, Save the Children International, UNAIDS, USAID Nepal, and three representatives of networks of key populations selected by the communities (National Association of People Living with HIV/AIDS in Nepal, National Federation of Women Living with HIV and AIDS, and a representative from the migrant community).

In the Democratic Republic of the Congo, involving authorities from the start allowed for faster approval by the ethics committee.

Figure 5 illustrates the different roles for a CLM project in Nigeria.

Figure 5. Partners and their roles in a CLM project in Nigeria



Comprehensive training of data collectors

Community data collectors are essential to the success of CLM. In-person and online training can enhance their skills and motivation. Training may include topics such as burnout, mental health, safety and security to ensure data collectors are emotionally equipped for their roles.

In Togo, CLM data collectors participated in online training led by ITPC West Africa and RAS+. The training sessions included information about HIV, qualitative and quantitative data collection techniques, and information about COVID-19. Following the training, participants showed a 16.2% improvement in knowledge levels.

Once CLM programmes are established

Coaching, mentoring and ongoing development

As CLM is rolled out and becomes established, organizations may need training in new skills such as data protection, digitalization and multiyear budgeting. In addition, capacity development may be needed to perform the full circle of CLM work, including critical steps such as evidence-based advocacy, facilitation and public speaking. Depending on the needs of the organization or context, this may include virtual support, site visits, south–south learning events and conventional training.

Invest in building positive relationships between health facilities and community monitors

CLM projects report that a key success factor is collaboration between health facility staff and community data collectors (21). If clinics see CLM as a way to strengthen their services rather than highlight their failures, they are more likely to take action when problems are identified. This collaborative relationship may also help to advocate for change on factors such as structural barriers beyond the control of people at facility level.

Keep the long-term focus on change

There may be pressure to see immediate changes or improvements, but successful CLM projects focus on the long-term changes that can occur as a result of their monitoring, not only data collection.

In Namibia, a CLM intervention in the Erongo community reported that key to its success was concentrating on “results and improvements to make services more accessible and acceptable”. Vast amounts of data are meaningless if they are not used to make concrete changes in peoples’ lives. Advocacy and strong data feedback loops are as important as robust data collection.

Publicly share CLM progress and results

Transparency is a core principle of CLM. The sharing of data and advocacy ensures CLM is accountable to the people it serves. In some countries, CLM implementers use social media and websites to keep communities informed about CLM progress.

Myanmar lays the groundwork for CLM implementation

In Myanmar, a community-led coalition is in the initial phases of launching a CLM pilot (31). The pilot is led by the Community Network Consortium (CNC), a coalition of eight national-level community networks—three networks of people from key populations, the national network of people living with HIV, the national network of women living with HIV, the national network of young people from key populations, a national nongovernmental organization and interfaith network, and the Myanmar Positive Group.

The Global Fund, PEPFAR and UNAIDS collaborated technically and financially to create a single CLM system for monitoring HIV service facilities around the country.

CNC carried out CLM and treatment literacy training to ensure the community understood the CLM process. CNC conducted community consultations to better understand the core issues facing people affected by HIV and to prioritize issues. A landscape assessment further identified current programming and gaps.

A CLM framework was created as a guiding strategy document, including monitoring and evaluation indicators.

The pilot is currently under way in 19 private health facilities in the states of Kachin, Mandalay and Yangon.

Although in many countries the initial CLM phases may be funded by donors, for the work to be sustained it is crucial to diversify funding sources, identify co-financing opportunities, and—importantly—improve government buy-in.

Case study: Malawi

Malawi is on the verge of controlling its HIV epidemic and achieving the global 95–95–95 targets: progress currently stands at 93–97–93. Despite this, there were an estimated 20000 new HIV infections in 2021, and people from key populations and children face treatment challenges (32, 33).

The goal of the Liu Lathu CLM project is to improve the quality, accessibility and affordability of HIV and TB services for people living with HIV and people from key populations. The project operates in six PEPFAR scale-up districts (Blantyre, Chikwawa, Lilongwe, Mzimba North, Thyolo, Zomba). It assesses 30 health facilities with a PEPFAR partner and has been active since October 2020.

The Malawi Network of AIDS Service Organizations is the lead CLM implementer. Data collection is structured around 13 core indicators, which include specific HIV and TB indicators but also broader health measures such as youth-friendly health services and governance and youth participation. A three-tier advocacy process elevates data analysis to the appropriate stakeholders, including the community, facility, district and national levels.

Results

- A new antiretroviral therapy clinic has been constructed at Malamulo Mission Hospital in Thyolo.
- Mikolongwe Health Centre in Thyolo now has a trained female nurse for cervical cancer screening to provide services to women living with HIV.
- Two new centres in Nathenje with community nurse-led antiretroviral therapy have been introduced.
- Mzuzu Health Centre has increased service provision with mobile clinics.

- Ekwendeni Mission Hospital has integrated antiretroviral therapy services in its outreach clinic to Kasasile and Luhomero villages.
 - Kafukule Health Centre has created a suggestion box for community members to lodge their ideas.
 - A broken fence at Zingwangwa Health Centre has been fixed, restoring the privacy of people attending the antiretroviral therapy clinic.
 - A GeneXpert Machine has been installed at Makhwira Health Centre in Chikwawa.
-

Enabling factors

- Key stakeholders were involved from the beginning.
 - Validation of tools with stakeholders increased buy-in.
 - Different civil society actors were involved, including people living with HIV, faith-based communities, people from key populations and youth.
 - The CLM model drew on three existing models (Compass, CTOs, Ritshidze) to create a context-specific model for Malawi.
 - Technical assistance allowed development of data-collection tools.
-

Challenges

- Delays in receiving funding halted the start of the activities and forced the implementation to be conducted in a shorter time than planned.
-

Key messages

- Despite a relatively short implementation period, the CLM intervention was able to demonstrate significant results in the form of improvements to health services.
 - The CLM intervention is in the process of being extended for an additional three years.
-

Implementation challenges

The following challenges have been documented in the work of several key organizations and the unpublished progress reports of CLM activities submitted to UNAIDS country offices.

Ensuring the principle of community-led

Although much progress has been made to ensure communities lead monitoring interventions, many communities still report that asserting their leadership is a challenge. Governments do not always buy in to core CLM principles, and well-meaning donors may interfere.

A 2022 survey of 35 CLM implementers led by the Community-led Accountability Working Group (CLAW) found that 29% and 22% of respondents felt that donors and governments (local and national), respectively, had attempted to challenge their project's independence (34).

CLM efforts are nascent or nonexistent in some communities. In these contexts, supporting community actors to engage with CLM is crucial.

Country-specific strategies are needed to support communities that work under particularly challenging political systems or in countries where governments are opposed to civil society engagement. Guidance and case studies on how communities have overcome government and donor resistance would be useful. Donors could be sensitized to respecting community independence while still fulfilling their own internal reporting obligations.

Owning and safeguarding data

Communities must retain and control CLM data in order for interventions to be community-led. A plan should be in place from the beginning covering how data will be safely stored, verified, analysed and shared with the broader community.

Beware of bureaucratic gridlock

CLM stakeholders should have clearly delineated roles and responsibilities. Outside consultants, technical assistance providers, technical agencies and others should be accountable to communities rather than to donors, technical partners or governments.

A community member in Namibia said: "Another frustration that I think was consistent across the implementing partners was around communications—especially with the roles of these consultants. I don't know what the consultants were doing. We were never formally introduced to any of the consultants. Consultants appeared, disappeared, appeared, disappeared" (35).

Managing conflicts of interest

As funding for CLM increases and new programmes launch, it is important to help implementers identify and address conflicts of interest around governance, funding and implementation. Proactively addressing conflicts helps CLM remain independent and effective.

The 2022 CLAW resource, *Conflict of Interest in Community-led Monitoring Programs*, can help countries address conflicts of interest (36).

Ensuring a robust and flexible CLM continuum

Focus on the full process rather than data collection

CLM is a process in which data are used to create change. If data are collected but not analysed or communicated to decision-makers, then CLM is not effective. Several of the CLM reports reviewed for this publication presented data but did not show the link to advocacy or change.

It is important to strengthen documentation of good practice on data analysis, the feedback loop to decision-makers for advocacy, and the changes that occurred as a result.

Maintain flexibility based on context

There is no one-size-fits-all CLM model. CLM cannot be implemented in the same way in every country. Strategies must be adapted to local conditions.

For example, in the Democratic Republic of the Congo, a pilot in Lubumbashi to shift from paper-based to digital data collection struggled due to lack of internet connection in remote areas. To adapt, the CLM implementer ITPC West Africa created an offline reporting process to use in addition to the digital data collection tools.

CLM plans should always be context-specific and allow for regular meetings to take stock of what is working and what needs to be adjusted. Donors and technical agencies should build flexibility into their funding streams and support processes to respond to challenges as they emerge.

Evaluation

Data gaps around results and impact

Many reports show how CLM has identified problems and barriers to care. With the notable exceptions outlined in this report, however, few reports focus on how identifying these problems has led to concrete changes. Sometimes positive changes are not quantified or documented in detail. For example, several reports indicate that CLM led to increased service access, without specifying further the size of the increase, or how CLM was responsible for the increased access.

Some CLM programmes report that services improved during the period of CLM monitoring, but it is difficult to prove causation without additional information and evidence supporting the link between the CLM monitoring and changes implemented by health facilities.

The global community of practice should discuss what is feasible to evaluate and how best to determine whether a CLM programme is having an impact, recognizing that CLM is only one factor contributing to improved health outcomes. At the same time, as several diverse CLM interventions for different diseases are rolled out in different countries, additional evidence will become available in the future as these models mature. Work is needed to document the results and outcomes of these pilots and ensure the data are widely accessible.

Measure how CLM increases meaningful engagement of communities in health responses

CLM models should define how they measure meaningful engagement. Many reports indicate that CLM increases the meaningful engagement of affected communities in national health responses but do not give details, making it difficult to replicate or better understand the process. Meaningful engagement of communities in national responses is multifaceted, including whether communities are consulted, participate in drafting funding requests, or serve on decision-making bodies.

Sustainability

Lack of strategic direction or short-term thinking

Although CLM can be deployed for rapid assessments and short periods, CLM is typically meant to be an ongoing programme rather than a one-off project. Time and resources should be invested in strategic planning for CLM interventions with all relevant stakeholders.

CLM programmes lack sustainable funding

A key challenge frequently mentioned in the documentation is that CLM is often funded for a year or less. Given that it takes several months to set up a CLM programme, such a timeframe is not possible to demonstrate significant results.

Some countries report that donors fund only one or two elements of the CLM process, often neglecting training of communities and the link between data and advocacy. Other countries report that data collectors are expected to work for free because they are from the community.

CLM needs dedicated multiyear funding. Data collectors should receive fair compensation and other benefits. Government buy-in and progressively having government co-financing of the CLM initiatives are important elements to securing longer-term sustainability of CLM. Continued documentation and collection of evidence of the positive impact of CLM and lessons learnt is useful.

Looking forward

The following recommendations are for governments, CLM implementers, technical assistance providers, technical agencies and donors. The suggestions draw on published literature and from a meeting to share lessons learnt held in Bangkok, Thailand in August 2022. This meeting, convened by the Global Fund, PEPFAR and UNAIDS, brought together over 60 CLM implementers, technical assistance providers, technical agencies and donors to discuss the future of CLM.

Governments

- Commit to investing in CLM systems as a key feature of systems for health, expressed in HIV national response plans, policies and budgets.
- Open spaces for civil society organizations to report CLM data and welcome their consideration in all decision-making related to public health priority-setting and policy and law reforms to enable people from key and marginalized populations to access equitable health care and justice, including repeal of provisions of criminal law that impede public health outcomes.
- Engage with CLM implementers, community-led organizations and networks, and technical agencies to understand and learn about the value of CLM in strengthening health and related social services.
- Work with CLM implementers and community-based organizations and networks to allow them to monitor health facilities and support regular meetings to learn the results.
- Encourage cross-ministry collaboration to address the issues flagged through the CLM cycle.

Implementers

- Develop a theory of change that incorporates a broader monitoring and evaluation framework to facilitate a continuous learning and improvement process. Build monitoring of the success of the overall CLM cycle into strategies and plans.
- Document and request technical assistance needs as they arise.
- Work with technical agencies to craft inputs, outputs, outcomes and process milestones to articulate the CLM progress.
- Be mindful of burnout and build support for CLM data collectors and programme staff into funding requests to ensure their well-being.
- Document stories, results, lessons learnt and qualitative data to use for advocacy.
- Develop sustainability plans for the continuation of CLM work.

Technical assistance providers

- Create a focused online and offline space where technical assistance providers can exchange information and troubleshoot challenges.
- Document emerging learning, particularly around south–south sharing of expertise, as well as results.
- Strengthen technical assistance offerings around the unmet needs of CLM implementers, such as working in a conflict or challenging operating environment.
- Leverage the power of technical assistance provider networks and broader global community networks to ensure technical assistance can be deployed rapidly and is flexible enough to accommodate issues as they arise.

Technical agencies

- Re-commit to the core principles and CLM models endorsed by the global community.
- Advocate for other United Nations agencies, technical partners, funders, technical assistance providers, global, regional and national networks, and community organizations to sign and adhere to these core principles.
- Support and work with CLM implementers and the broader stakeholders for quality-assured CLM implementation and addressing the needs for any improvements against the CLM principles through inclusive processes and use of tools, like the UNAIDS self-assessment CLM Progression Matrix.
- Establish and strengthen partnerships with other disease responses and other sectors to expand the global community of CLM practice.

Donors

- Directly fund CLM implementation. Where possible, increase direct funding to community-led partners, organizations and networks, reducing overhead costs associated with pass-through mechanisms.
- Consider pooled funding options, including establishing new pooled funding mechanisms and expanding or diversifying existing mechanisms. Pooled funding is ideal for creating flexible and responsive small grants for community-led organizations.
- Increase donor coordination on technical assistance and CLM implementation, strengthening the ability of donors to respond rapidly to emerging issues at the country level across donor agencies.
- Contribute to the CLM global and regional community of practice by sharing case studies, best practices and lessons learnt, particularly through community-led partners, organizations and networks.
- Engage with and open spaces for community-led partners, organizations and networks to liaise with governments on the value of supporting CLM, helping to address scepticism and broaden awareness of the positive impact.
- Invest in developing community technical assistance providers from key populations and organizations and networks of people living with HIV, including supporting their coordination work.

Annexes

Annex 1. CLM definitions and descriptions³

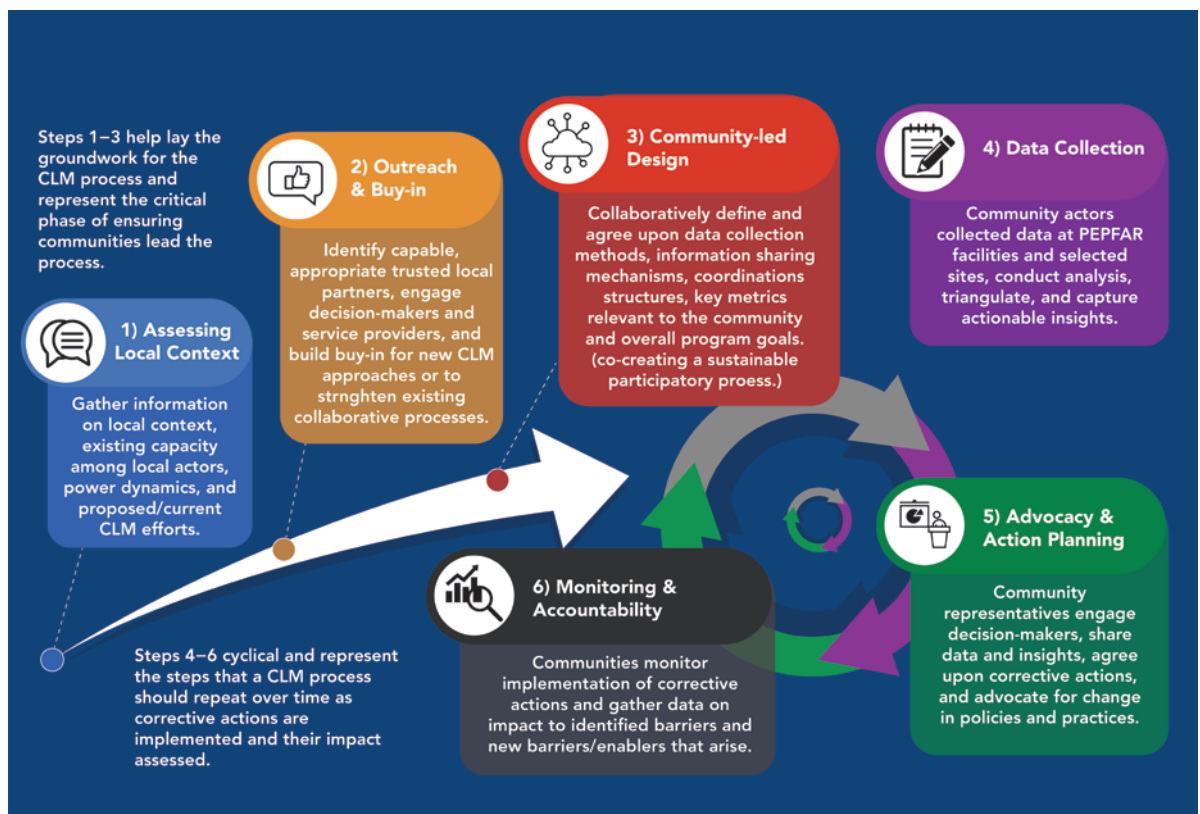
Global Fund

CLM is an accountability mechanism that uses an independently structured and planned process designed and led by equipped, trained and paid members of community-led organizations of affected communities, to systematically and routinely collect and analyse quantitative and qualitative data from health service delivery sites (facility-based and beyond) and affected communities either for a specific disease component (HIV, HIV/TB, TB, malaria) or for broader primary health care (37).

PEPFAR

CLM is a process initiated, led and implemented by local community-based organizations and other civil society groups, networks of people from key populations, people living with HIV, and other affected groups or other community entities that gathers quantitative and qualitative data about HIV services and develops and advocates for solutions to the gaps identified during data collection. The focus is

Figure 6. PEPFAR CLM process map



³ This is not an exhaustive collection of the definitions from partners and technical support agencies.

on getting acting input from recipients of HIV services, especially people from key populations and underserved groups, in a routine and systematic manner that will translate into action and change (14).

ITPC

CLM is a critical part of data collection, allowing communities to identify real-time gaps in access and provide new insights about the state of a country's HIV and broader health response. CLM covers four key areas: education, evidence, engagement and advocacy. When communities have tools and techniques to collect and analyse their own data, they are able to increase domestic oversight and conduct evidence-based advocacy to improve services for HIV and related conditions.

CLAW

CLM is an essential social accountability mechanism used by communities to watchdog the quality and accessibility of health services for HIV, TB and malaria, as well as newer pandemics such as COVID-19, and related health justice priorities such as access to sexual and reproductive health services. CLM empowers communities to develop solutions to problems identified through the systematic collection of data at health facilities and in communities. Through a five-step cycle, community monitors collect information at the facility and community levels; translate their data into actionable insights; bring information to the attention of facility, government, and donor decision-makers; advocate for changes in policy and practice when facility level decision-makers can't—or won't—resolve problems; and finally, monitor whether or not changes that have been promised to communities have actually been delivered. This cycle of accountability building is then repeated.

Stop TB Partnership and TB communities

CLM empowers people affected by TB to voice opinions, access services, respond to challenges, co-create solutions and advocate for change. Through community-led and country-owned processes, OneImpact CLM encourages and facilitates the participation and collaboration of people affected by TB with TB programmes to activate a human rights-based, people-centred response. In doing so, CLM combats the central TB challenges in the TB response at the individual and community levels, while generating essential information to better understand and combat them at the programmatic level to end TB.

Annex 2. Further reading

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