COMMUNITY-LED MONITORING

Best practices for strengthening the model

White Paper

This paper clarifies the principles behind community-led monitoring of health services, a methodology that uses systematic data collection by communities for evidence-based advocacy to improve accountability, governance and quality of health services.

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Context

Community-led monitoring (CLM) is a powerful model for improving the quality of healthcare services, by empowering communities with data to advocate for change. In the CLM model, service users and directly-impacted communities lead a systematic data collection effort, in which the community itself decides which issues should be tracked, creates indicators, and collects facility- and community-level data. These data are then analyzed and used to support advocacy directed at government and donors, with the aim of improving accountability and improving the quality of healthcare services. What differentiates CLM from typical efforts to improve health service quality is its accountability function: CLM is developed by and for communities using the services being monitored in order to uncover and correct problems undermining access to quality health services.

In February 2020, the Global Fund held a global meeting in Geneva, entitled "Towards a Common Understanding of Community-based Monitoring and Advocacy."[1] This meeting brought together implementers, donors, and other stakeholders to review the current understanding of CLM. Several key findings from this convening were summarized in a white paper that created a first definition of the CLM model.[2]

Two years since this convening, CLM implementation has expanded dramatically. Since COP20, PEPFAR has required all programs to develop and support a CLM program[3] and the Global Fund Strategy has signaled a strong commitment to "putting the community at the center," in part through scaling up investments in CLM.[4] On the basis of a global survey conducted in early 2022[5], organizations in nearly 30 countries have reported participating in community-led monitoring of HIV, tuberculosis, malaria, human rights, or COVID-19.

In August 2022, a second global convening on CLM was held by Global Fund in Bangkok, with the aim of working "Towards a Global Agenda for Community-Led Monitoring"[6]. During this meeting, 66 CLM implementers and technical assistance providers[7] were invited to a three-day meeting to review the findings, experiences, and lessons learned from CLM implementation. This report presents a global consensus that emerged from the meeting, including the fundamental stages of the CLM cycle, the core principles of CLM, and recommendations for strengthening CLM.

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[1] The Global Fund. Towards a Common Understanding of Community-based Monitoring and Advocacy. February 2020. Geneva Switzerland.

[2] Health GAP, HEPS-Uganda (the Coalition for Health Promotion and Social Development), ICWEA(The International Community of Women Living with HIV Eastern Africa), ITCP (International Treatment Preparedness Coalition), O'Neill Institute for National and Global Health Law, SMUG (Sexual Minorities Uganda), TAC (Treatment Action Campaign). Community-Led Monitoring of Health Services: Building Accountability for HIV Service Quality (White Paper).

[3] PEPFAR. PEPFAR 2020 Country Operational Plan. Guidance for all PEPFAR Countries. January 2020. Pg. 96.

[4] The Global Fund. Fighting Pandemics and Building a Healthier and More Equitable World. Global Fund Strategy (2023-2028).

[5] CLAW. Best Practices for Community-Led Monitoring. September 2022.

[6] The Global Fund. Towards a Global Agenda for Community-Led Monitoring. Meeting Report. 29 August - 1 September 2022. Bangkok, Thailand.

[7] The EANNASO-ATAC-APCASO, CD4C, and CLAW consortia have served as CLM technical assistance providers and have been supporting the establishment and development of CLM programs since 2021 for Global Fund funded programs and earlier engaging with different CLM programmes funded by different donors. The three consortia have been providing Global Fund-supported technical assistance to CLM programs as part of the COVID-19 Response Mechanism (C19RM) and the current Strategic Initiative for CLM. These activities have included short-term assistance to CLM programs and the development of resources and tools on CLM implementation.

Main activities in the CLM cycle

As CLM implementation grows worldwide, participants in the convening identified a critical need for a global consensus on the core minimum activities needed to implement a functioning program. The minimum activities needed to implement the CLM cycle, as agreed in Bangkok and building on previous guidance from technical assistance providers[8,9,10], and UNAIDS[11], are defined below.

Pre-data collection

The pre-data collection phase includes prerequisite activities designed to prepare the program for data collection and advocacy. This stage involves identifying one or more local community-based organizations to lead the CLM program, often with efforts to build organizational capacity for program and grant management, support community empowerment and treatment literacy, and build understanding of the CLM model.

The lead organization then undertakes a phase of planning and program conceptualization, often involving soliciting funding, developing workplans, and orienting government and other duty-bearers to CLM. Finally, the CLM implementer will identify from the community the needs and gaps in service provision and, drawing on those findings, develop and pre-test indicators, data collection software, and other tools.

Data collection and analysis

After the local implementation lead has been identified, the program's advocacy priorities have been identified, and the data collection tools have been developed, the next phase is data collection. Depending on the program's priorities and disease focus, this can involve any combination of surveys, individual interviews, and focus groups, collected in clinics, the surrounding communities, and/or in respondents' homes. These data are then analyzed by the implementation team. Finally, meetings with both the CLM implementer, civil society organizations, and the broader community are held to analyze the information and translate data into actionable insights and advocacy priorities.

Developing solutions and conducting advocacy

Once the gaps and issues in service provision have been identified, the CLM program develops actionable, data-informed solutions to the gaps that have been identified. These advocacy messages are disseminated through targeted action to bring proposed solutions to the attention of decision-makers at the facility, regional, national, and international levels. This advocacy is typically conducted by a combination of re-visiting clinics, establishing Community Consultative Groups, and/or by leveraging existing policy- and decision-making forums and governance structures. The CLM program advocates for decision-makers to implement broader changes in policy and practice through public-facing Community Accountability Meetings, reports like the People's COPs, and more.

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[8] CLAW. Community-Led Monitoring of Health Services: Building Accountability for HIV Service Quality (White Paper). December 2019.

[9] Solange B. Community Data Matters: A Look Into Community-Led Monitoring. International AIDS Conference 2022.

[10] EANNASO. Community-Led Monitoring: A technical guide for HIV, tuberculosis and malaria programming.

[11] UNAIDS. Establishing Community-Led monitoring of HIV services. February 2021.

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Follow-up and monitoring   After the data collection and advocacy phases, the CLM program continues its monitoring and follow-up to ensure that commitments from duty-bearers are enacted, as well as to identify trends and impact. Additionally, the CLM program continually monitors its own impact and performance to ensure that the program remains impactful, often involving a phase of revising data collection tools and advocacy strategies as community needs and priorities evolve. Finally, CLM programs routinely provide feedback to the community regarding the outcomes of its advocacy and how CLM data have been used.

Global alignment on the core principles of CLM

A **key output** of the Bangkok meeting was a clear shared definition of the underpinning core principles of the CLM model. The convening participants identified these principles as being essential requirements for a CLM program to both achieve impact and avoid common implementation and governance challenges. This definitions finds that CLM programs *must*:

01. Be led by directly-impacted communities, including people living with HIV, TB and/or malaria and key populations;

02. Maintain local leadership and independence, protecting against programmatic interference from other actors including donors, national government, and other monitoring and evaluation systems;

03. Be owned by communities in every stage, including identifying priority issues in the community, defining indicators, establishing preferred channels of communications with partners, and deciding how data are housed and used;

04. Include advocacy activities aimed at generating political will and advancing equity, given CLM's fundamental function as a social accountability tool;

05. Adhere to ethical data collection, consent, confidentiality, and data security. Data collection must be verifiable, reliable, conducted in a routine/continuous cycle and collected under 'do not harm' principle;

06. Ensure that data are owned by communities, with programs empowered to share CLM data publicly and at their discretion. CLM programs should not be made to re-gather, replace, or duplicate M&E data from existing systems;

07. Ensure community monitors are representatives of service users, and that they are trained, supported, and adequately paid for their labor, while maintaining the community independence from the donor;

08. Be coordinated by a central, community-owned structure capable of managing the programmatic, financial, and human resource components of the program.

Successes from CLM implementation

Many of these programs have already demonstrated promising results, despite nearly all programs being just one or two years into implementation.

In Malawi, advocates used CLM data to successfully advocate for increased funding for viral load testing during the PEPFAR COP22 planning process.[12]

In South Africa, advocates have used CLM data to secure 1,285 commitments from facility managers in 391 clinics to address gaps in healthcare delivery, contributing to large improvements in service delivery, including increasing access to PrEP and GeneXpert testing, improving treatment literacy, reducing stock-outs and shortages, and improving clinic hours and wait times.[13]

In Sierra Leone, the CLM program successfully advocated for the National AIDS Control Program (NACP) to establish a new national indicator to capture ART treatment interruption and loss to follow-up during the COVID-19 pandemic.[14]

In India, CLM data revealed that large decreases in TB diagnoses were due to misinterpretation of recent government guidelines, resulting in patients being incorrectly required to test for COVID-19 before TB screening. The CLM team held dialogues to address the misinterpretation, with mandatory COVID-19 testing ultimately removed as a barrier to access.[15]

In Haiti, members of the Community Observatory of HIV Services (OCSEVIH) of the Civil Society Forum successfully advocated for clinic staff to document whether women on HIV treatment have been screened for cervical cancer, to provide care for PLHIV in private rooms instead of shared spaces, to fully repaint and clean up a clinic in disrepair, and hire new social workers in order to reduce wait times.[16]

Recommendations

Despite gaining recognition as a crucial accountability mechanism that has registered early successes, several key challenges to successful implementation have emerged, which have acted as barriers to programs' ability to implement all phases of the CLM cycle. Importantly, the model is under- and unevenly funded in ways that undermine civil society ownership and attention to the full spectrum of issues impacting health equity. Components of this problem include: unpredictable funding and funding flows, imposition of donor agendas and some funders' (and CLM implementers') reluctance to engage in robust critical accountability work when the target is also the funder.

These recommendations draw on the experiences of the CLM implementers and technical assistance providers present in the Bangkok convening, as well as findings from a broader research study on CLM best practices.[17]

Ensure the independence and community leadership of CLM programs

Experience from two years of CLM implementation indicate that safeguarding and nurturing CLM independence is a major challenge.Fundamental to the CLM model is the principle that program leadership and ownership must sit within the community and local civil society, and not with donors, governments, health facilities, or other partners. Because CLM monitors the quality and accessibility of donor and government-provided

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[12] Mitsunge M. Lifting up key populations voices and increasing quality of HIV services in Malawi: using community led monitoring to strengthen services for KPs and people living with HIV. International AIDS Conference 2022

[13] Anele Y. Evaluation of Ritshidze community-led monitoring in South Africa. International AIDS Conference 2022

[14] Solange B. Community Data Matters: A Look Into Community-Led Monitoring. International AIDS Conference 2022

[15] Solange B. Community Data Matters: A Look Into Community-Led Monitoring. International AIDS Conference 2022

[16] Soeurette P. Barriers impeding care for people living with HIV: early findings from Community-Led Monitoring in Haiti. International AIDS Conference 2022

[17] CLAW. Best Practices for Community-Led Monitoring. September 2022.

services it requires strong independence from those actors without which CLM programs rapidly turn into community projects focused solely on data collection and sharing rather than on advocacy to overcome chronic health systems failures that cannot be resolved at the health facility level.

While playing a vital role as partners to CLM programs and providers of assistance, donors and governments must not decide on behalf of CLM programs which sites to monitor and which indicators should be included in surveys. Similarly, donors and governments must adhere to the principle of data ownership by CLM projects[18], including ensuring that CLM data are not stored in government databases (such as DHIS2 instances owned and operated by Ministries of Health) or donor systems (such as PEPFAR's Datim). Rather, they are owned by communities, who decide how and when to share these data with stakeholders[19].

Furthermore, in the cases where organized communities who could lead advocacy efforts are not yet established, investment should focus on enabling the environment in which CLM could have a chance of being developed and succeeding. CLM interventions cannot be fast-tracked at the expense of essential work of community mobilization where community networks to implement CLM are not yet established.

Fund CLM programs on time and in full

Evidence from CLM programs reveals inadequate budgets, with routine donor disbursement delays and challenging restrictions on funding for key budget areas (such as payment for community monitors).

Funding levels for CLM projects must be adequate and predictable to enable programs to implement the full cycle of CLM activities. Specifically, it is essential that donors fund not only the data collection activities, but the full suite of core activities needed to successfully implement CLM. This must include funding for the pre-data

collection phase, including building community engagement, soliciting buy-in from stakeholders, developing community governance structures. Additionally, data collection budgets must sufficiently fund electronic tools for data collection, such as tablets, and developing and maintaining a standalone, secure data warehouse.

CLM programs must also be funded to provide adequate remuneration of all CLM participants, including the data collectors, advocates, and dedicated staffing for data analysis and advocacy. Programs must be funded to deliver trainings, develop and evolve data collection tools and indicators, and to reimburse the team for implementation-related travel. Additionally, budgets must adequately support advocacy activities, including regular meetings and development of advocacy material and activities of community education, communications and advocacy, and holding community consultations and feedback activities in clinics.

Many community implementers rely on in-kind support from a wide range of partners (for example, M&E support from other staff members, partners or allies during busy data analysis moments) that mask the true costs of CLM. CLM budgets should be robust and support the full complement of staff time needed to implement programs at scale without relying on in-kind support.

Finally, on-time disbursement of funds is a significant concern raised by many CLM programs. Delays in receiving funding can result in termination of staff contracts or result in programs not being able to complete the full cycle of data collection and advocacy, as well as introducing uncertainty and an inability to plan program activities. Ensuring that funds are transferred on time and in full is vital.

[18] UNAIDS. Frequently asked questions: Community-Led Monitoring. 2021.

[19] CLAW. Conflict of Interest in Community-Led Monitoring programs. 2021.

Promote funding mechanisms best suited for CLM

Donors should fund CLM programs through mechanisms that are preferred by the community organizations implementing programs and that safeguard community independence. In some cases, CLM implementers may prefer for donors to directly fund community organizations leading the program. However, donors often do not directly fund unregistered civil society organizations, particularly key population led CLM implementers, due to policy restrictions–despite the fact that those groups might be best equipped to carry out CLM. During the last two years of CLM implementation, straightforward "pass-through" mechanisms that provided funding directly to civil society from other streams that do not have those restrictions, helped mitigate this challenge to independence.

Where neither option is possible, or where CLM programs do not have the desire or capacity to independently manage the funding stream, experience from technical assistance providers suggests that small grants to individual implementers are logistically challenging and hinder the ability of communities to deliver a coordinated, coherent national program. Coalition or consortium proposals detailing the coordination, funding, and inclusion structures should be preferred, in order to avoid divisions in society and delays in disbursement and program roll-out.

In cases where community organizations are not eligible to receive funds directly or do not have sufficient grant management capacity, alternative mechanisms that limit the number of pass-throughs, avoid conflicts of interest (e.g. with governmental PRs), reduce overhead, and preserve project independence should be prioritized. Coordinated CLM donor and technical agency approaches, through funding mechanisms that pool resources from multiple donors, are recommended.

Measuring CLM success

The goals of CLM programs are long-term and require sustained engagement with a variety of duty-bearers over time. Fundamentally, CLM implementers are not in control of whether the services being monitored actually improve; rather, that power lies with the ministries of health and

donor-funded programmatic implementing partners that are often the targets of CLM advocacy.

Requiring impact evaluation as a measure of success at this nascent stage of global rollout is not realistic nor justified, even while early results are seen in some countries.

Imposing impact evaluations and tying funding decisions to such evaluations are counter-productive at this stage. Instead, we recommend jointly defining what success looks like in the short-, medium- and long- term phases of CLM evolution and working together on progress assessment approaches that could be defined and measured, bearing in mind significant variations in context.

A tool to close the gap

As the world approaches 2025, the need to address key gaps in access and uptake of healthcare services is critically needed for achieving the 95%-95%-95% targets. Community-led monitoring offers an important strategy for redressing accountability gaps by building power in communities, holding duty-bearers accountable to the needs of healthcare service users, and developing actionable improvements and recommendations that build on granular clinic data.

CLM does not replace the longtime efforts by people living with and affected by HIV, TB and malaria to demand action from governments. If properly implemented and adequately funded, CLM can be a powerful additional tool to support communities to demand the provision of effective programs to help end the three diseases while addressing service uptake and retention challenges and removing gender and human rights-related barriers, for more equitable healthcare for all. As the Global Fund's NFM4 and PEFPAR's Annual COPs process are poised to infuse significant funding into CLM, understanding the core principles of the methodology and implementing them with fidelity is more important than ever.

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