LESSONS LEARNED IN COMMUNITY-LED MONITORING:
early evidence from the global implementation landscape

Alana Sharp[1], Ngqabutho Mpofu*[2], Chamunorwa Mashoko[3], Stefanie Dringus[1], Brian Honermann[4], Asia Russell[5], Karyn Kaplan[6], Beatrice Ajonye[7], Mtisunge Mikaya[8], Ndivhuwo Rambau[9], Claudia Aguiar[1], Ngozi Erondu[1], Elise Lankiewicz[4], Naïké Ledan[3], Matthew M. Kavanagh[1]

[1] Georgetown University, O'Neill Institute for National and Global Health Law, United States, [2] Treatment Action Campaign, South Africa
[3] Advocacy Core Team, Zimbabwe, [4] amfAR, Public Policy Office, United States, [5] Health GAP, United States, [6] Asia Catalyst, Thailand, [7] International Community of Women Living with HIV Eastern Africa,[8] MANASO, Malawi, [9] Ritshidze, South Africa

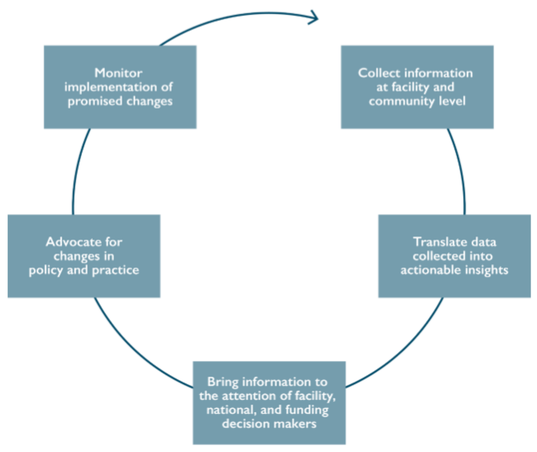
INTRODUCTION

Achieving the global 95-95-95 targets is critically dependent on finding the missing positives, addressing unacceptably high loss to follow-up rates and reengaging people living with HIV into treatment and care. Community-led monitoring (CLM) is an important approach for improving the quality of healthcare services through social empowerment and political accountability.

CLM is based on three key principles[1] that are consistently present across CLM definitions by the Global Fund[2], PEPFAR[3], and UNAIDS[4]:

1. Community-led monitoring requires leading and ownership by independent communities/civil society.
2. Community-led monitoring requires organized communities for effective monitoring.
3. Community-led monitoring focuses on generating political will to enact change and ensure accountability of decision-makers and other duty bearers.

COMMUNITY-LED MONITORING CYCLE



Driven by increasing support from donors, a growing number of countries are implementing CLM, creating an optimal time to identify early best practices in CLM implementation.

This analysis builds on an important body of work defining CLM and its core tenets, developed by CLM projects like UNAIDS[5], and global technical assistance consortia such as the Community-Led Accountability Working Group (CLAW)[1], Community Data for Change Consortium (CD4C)[6], and the EANNASO-APCASO-ATAC consortium[7]. However, as several CLM projects conclude their first years of implementation, this is a critical moment to evaluate country experiences, learn from key challenges and successes, and define effective approaches for CLM implementation.

STUDY OBJECTIVE

This analysis presents empirically-derived guidance and best practices for CLM implementation, from a global exploration of real-world implementation and suggestions from CLM implementers themselves. Best practices are elements and considerations that help deliver CLM more effectively, and are aligned with core values and principles of the approach.

In keeping with the principles of community-based participatory research, all tools and resources were designed with and for the benefit of CLM projects and the communities they represent and serve. As such, the data collection tools were developed using a consultative process to ensure that survey instruments were not only technically sound, but also prioritized collecting information on key issues and themes that would be valuable to CLM implementers and their allies.

METHODS

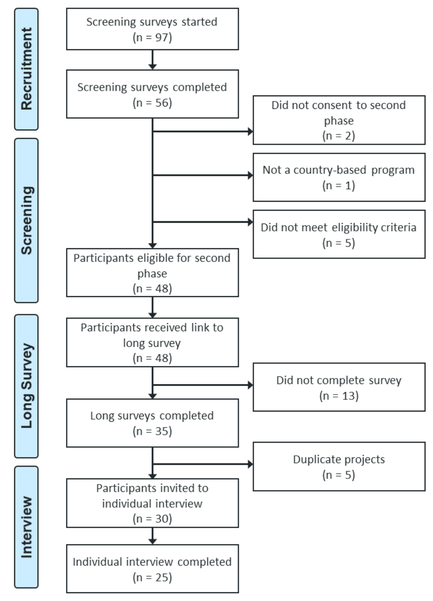
PARTICIPANT RECRUITMENT

"Challenges" and "best practices" in CLM implementation were drawn from data collected from current or past CLM implementers. Participants were recruited electronically using a brief screening questionnaire that gathered informed consent and data on key parameters of the participants' CLM project. The screening questionnaire was available in English, French, Portuguese, Spanish, and Russian.

After completing the brief screening questionnaire, CLM projects that met two of the three following inclusion criteria were invited to participate in the second phase of data collection:

1. Project implementation is led by a local civil society organization; key, vulnerable, or priority populations; and/or people living with or impacted by HIV, tuberculosis, or malaria;
2. Project activities include collecting data on healthcare quality and access; and
3. Project activities include advocating for solutions and working with decision-makers for change.

Figure 1. Recruitment overview.



DATA COLLECTION AND ANALYSIS

The second phase of data collection consisted of a longer, more in-depth quantitative questionnaire, followed by a tailored, semi-structured interview, exploring the implementation of CLM projects in greater detail (**Fig. 1**).

Once a CLM project had completed the quantitative questionnaire, they were invited to a qualitative interview to discuss in-depth, key aspects of their project, with a particular focus on challenges, successes, key learnings, and recommendations for best practices. Interviews were conducted on recorded Zoom or phone calls in the respondent's preferred language.

Challenges were defined as practices or occurrences that challenged CLM projects' abilities to deliver on their strategic objectives. Best practices, by contrast, were either described as having been a helpful practice or one that implementers would suggest to other CLM projects as a valuable practice.

RESULTS

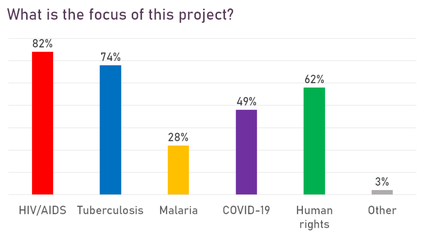
DESCRIPTION OF PARTICIPANTS

Between 13 January and 8 February, 2022, 97 participants consented to participate in the project, of whom **60 respondents from 29 countries completed the initial screening** survey. Thirty-five eligible respondents, representing 23 countries, completed the long-form survey. The majority of countries represented were in Sub-Saharan Africa (77%), with additional representation from Asia (17%), Europe (3%), and Latin America and the Caribbean (3%). In 9 of the 23 countries represented, multiple respondents per country completed the initial survey.

Figure 2. Regions represented by long-form survey respondents

The majority of respondents that participated in the long survey were either staff at an organization leading the CLM project (72%) and/or community members involved in the project (26%). Most projects (82%) monitor indicators related to HIV, and 74% include TB indicators **(Fig. 3).**

Figure 3. Survey responses to focus of project



Most (61%) participants in the long survey identified the Global Fund to Fight AIDS, Tuberculosis and Malaria as a current or former source of funding for CLM projects. Other commonly-identified donors included PEPFAR (identified by 37% of participants), a United Nations agency (16%), the U.S. State Department Ambassador's Small Grants Program (11%), and GIZ (11%). Less commonly-identified donors included the Stop TB Partnership (8%) and Expertise France/French 5% (8%).

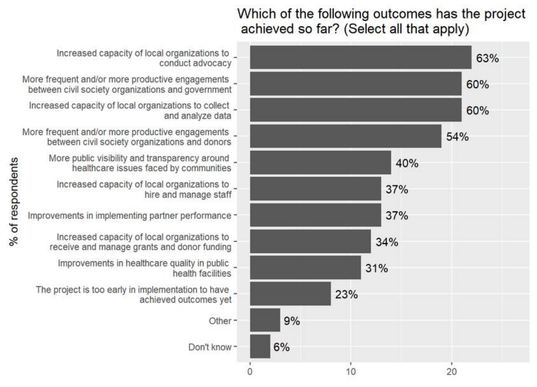
BEST PRACTICES IN CLM

The most common success achieved by CLM projects was **increasing the capacity of local organizations**, including to conduct advocacy (reported by 63% of respondents), gather data and analyze data (60%), hire and manage staff (37%), and receive and manage grants (34%) (**Fig. 4**). To develop organizational capacity, respondents described the need to build dedicated, specialized teams; invest in ongoing training for CLM teams; and build capacity for organizations to solicit and receive funds.

In addition to benefiting local community groups, CLM projects were also described as creating more frequent and **more productive engagements between civil society and governments** (60%) and donors (54%). Interviewed participants described the importance of early stakeholder engagement with governments and civil society networks to build buy-in and support for CLM.

Respondents suggested **addressing challenges around data** use by ensuring community ownership of data, promoting data transparency and access, gathering data using modern, digital data collection and analysis tools, and field testing surveys to ensure appropriateness and clarity.

Figure 4. Survey responses to the outcomes achieved by the CLM project



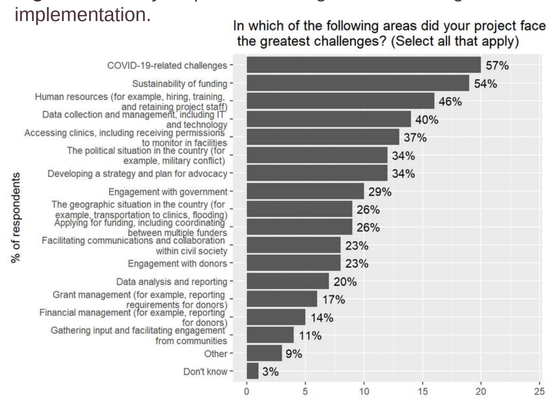
A key best practice identified by respondents was **ensuring adequate funding for the advocacy** component, by developing strong workplans for advocacy and costed advocacy budgets for donors. Respondents also described the importance of hiring dedicated advocacy staff to the core CLM teams, as well as continuously engaging stakeholders and duty-bearers throughout the CLM cycle to build mutual ownership and trust.

CHALLENGES IN CLM

According to participants in the long-form survey, the most common challenge faced by CLM implementing projects was COVID-19 (reported by 57% of participants), mostly due to travel restrictions, economic hardship, stakeholders being focused on COVID, and the need to adapt monitoring frameworks to add COVID indicators. (**Fig 5**).

During project set-up, respondents described challenges with hiring and retaining project staff and coordinating multiple community-based organizations. Other challenges included the political situation in the country (34%), engagement with government (29%), and challenges to the independence of the project by donors (29%) and/or government (22%).

Figure 5. Survey responses to the greatest challenges in implementation.



Funding challenges were common, with 88% of respondents reported not having enough funding to do the activities they would like to do, and 54% identifying sustainability of funding as a challenge. On-time funding from donors was an area of concern, with 66% of respondents reporting that funding is sometimes, often, or always delayed.

According to 40% of projects, **data collection and management** are a key challenge, driven by insufficient budgets, inappropriate indicators and poor survey design, lack of electronic data collection equipment, conflicts around data ownership, and issues around technical capacity to analyze large volumes of data.

The most common **challenge when conducting advocacy** was insufficient funding (reported by 65% of respondents) and delays in receiving funding (38%). Advocacy was often deprioritized due to lack of funding or not adequately budgeted for. Other challenges included not having enough staff or volunteers to conduct advocacy (27%), with just 17% of respondents being able to pay their advocacy staff.

CONCLUSIONS

The findings from this analysis present important and actionable insights into the challenges and successes faced by CLM implementing organizations. The consideration and option of these recommendations by CLM implementers, technical assistance providers, donors, governments, and allied institutions will be critical to ensuring the ability of CLM to improve healthcare quality. While these findings represent the lived experiences and beliefs of CLM implementers, future work is needed to continue identifying impactful and novel approaches for CLM implementation.

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