Community-Led Monitoring Global Convening

Joint position statement from technical assistance providers

Bangkok, August 2022

We, as consortia of civil society networks and organisations supporting in-country CLM work worldwide, ask for solidarity from the convened donors in publicly articulating and championing high-quality, well-funded, and high impact CLM interventions. Missing this moment will allow inadequate and poor-quality health services to continue unchecked. CLM provides a unique and essential avenue for improving services, outcomes, efficiency of programming and accountability to communities, but not when it is poorly funded, poorly supported, or poorly structured.

Drawing on the collective experience of the undersigned organizations, we request that donors and technical agencies stand with us in committing to a joint understanding and promotion of core CLM principles, and urgently change course where this is not taking place. We believe the actions we call for below will result in urgent improvements in CLM implementation.

Background

Community-led monitoring (CLM) is a powerful model for improving the quality of healthcare services, in which healthcare service users and communities directly impacted by the health issues lead the routine collection and analysis of health system data to conduct data-informed advocacy efforts, on issues they identify as priorities, for lasting positive change. On the basis of a global survey[1] conducted in early 2022, **organizations in nearly 30 countries have reported participating in community-led monitoring** of HIV, tuberculosis, malaria, human rights, or COVID-19.

According to the survey of CLM implementers[2], the most common funders of CLM programs are the Global Fund (funding 61% of respondents) and PEPFAR (37%). We note that, since COP20, PEPFAR has required all programs to develop and support a CLM program[3] and the recent Global Fund Board approval of a potentially significant increase in catalytic investments for CLM in the 2023-2025 allocation cycle.[4] As such, **this Community-Led Monitoring Global Convening is an important opportunity to review the lessons learned from CLM implementation to date and for CLM donors and other stakeholders to develop a roadmap for improving CLM impact going forward**.

[1] Best Practices for Community-led Monitoring: Global survey on challenges, Best practices and recommendations for CLM programmes as presented by current CLM programmes. Expected publish in September 2022

[2] Ibid 1

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

[4] The Global Fund. GF/B47/04 Revision 1. Catalytic Investments for the 2023-2025 Allocation Period. May 2020.

Core principles of CLM

The strength and effectiveness of CLM initiatives rely on the strength and effectiveness of communities and civil society to lead them. As such, support for CLM cannot go without support for the mobilisation and strengthening of community-led and civil society networks and organisations and without investments for strengthening of country and regional community systems as part and parcel of resilient and sustainable systems for health.

Drawing on definitions developed by the under signatories[5][6][7] and complemented by guidance from the Global Fund[8], UNAIDS[9], and PEPFAR[10], there is a clear shared definition of community-led monitoring and the underpinning core principles. **This definition finds that CLM must:**

1. Be independent from its donors and from national governments,
2. Be built by communities–from identifying priority indicators to preparing questions and defining preferred channel of communications, for monitoring to owning and housing the data;
3. Be led by directly impacted communities–people living with HIV, TB and/or malaria and key populations,
4. Include advocacy activities with the aim of generating political will, based on its fundamental watchdogging function, while focusing on advancing equity and accountability,
5. Adhere to ethical data collection, consent, confidentiality and data security. Data collection must be verifiable, reliable, conducted in a routine/continuous cycle and collected under "do not harm" principle
6. Ensure that data are owned by communities, with programs empowered to share CLM data publicly. CLM programs should not be made to re-gather or duplicate M&E data from existing systems.
7. Ensure monitors are representatives of service users, and that they are trained and supported and adequately paid for their labor, while maintaining the community independence from the donor,
8. Be coordinated by a central, community-owned structure capable of managing the effort

[5] Ibid 7. (CLAW. Community-Led Monitoring of Health Services: Building Accountability for HIV Service Quality (White Paper).)
[6] ITPC. Community-Led Monitoring Brief.
[7] Ibid 6. (EANNASO. Community Led Monitoring: A technical guide for HIV, tuberculosis and malaria programming).
[8] Global Fund. Community-based monitoring: An Overview.
[9] Ibid 4. (UNAIDS. Establishing community-led monitoring of HIV services.)
[10] PEPFAR. Community-led Monitoring (Factsheet).

The models/cycles of CLM activities, as defined by CLAW[11], ITPC[12], EANNASO[13], and UNAIDS[14], includes the following key stages of activities:

1. *Pre-data collection:* Identification of local community-based organization(s) to lead the CLM program; community and government orientation, community empowerment, and capacity building including community treatment literacy; relationship building, planning and conceptualization phase; identification of community needs and gaps from the affected community; and indicator development and pretest of data collection software and tools;
2. *Data collection and analysis*: Collecting information at facility and community level; analyzing data; and conducting community meetings to analyze the information and translate data into actionable insights and advocacy priorities;
3. *Developing solutions and conducting advocacy:* Targeted action to bring information and proposed solutions to the attention of facility, national, and funding decision-makers (often through the establishment of Community Consultative Groups or leveraging other existing policy- and decision-making forums, or governance structures); and advocating for changes in policy and practice and work together with decision-makers to implement change, for example through Community Accountability Meetings, People's COPs, and more.
4. *Follow-up and monitoring:* Following up with duty bearers to monitor implementation of promised changes; analyzing the effectiveness of the CLM program and continually improving; and monitoring the change, looking for trends and impact.

Key Challenges to Address

The current overarching CLM challenge lies in implementing effective CLM programs (that run the full CLM cycle) without violating core CLM principles.

The success and impact of CLM programs are closely tied to their ability to implement activities that are aligned to the core CLM tenets and include all phases of the CLM cycle. As such, we call on governments, donors, technical agencies and technical assistance providers to adopt the principles of CLM, supporting all phases of the CLM cycle and acting as global champions for a model of CLM that can deliver impact.

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

[12] Ibid 1. (Solange B. Community Data Matters: A Look Into Community-led Monitoring. International AIDS Conference 2022.)

[13] Ibid 6. (EANNASO. Community Led Monitoring: A technical guide for HIV, tuberculosis and malaria programming).

[14] Ibid 4 (UNAIDS. Establishing community-led monitoring of HIV services.)

Issue 1: Independence and community leadership of CLM programs are compromised when donors and technical agencies prescribe what must be monitored and who should do the monitoring.

Fundamental to the CLM model is the principle that program leadership must sit within the community and local civil society, and not with donors, governments, health facilities, or other partners. While playing a vital role as partners to CLM programs and providers of assistance, donors must not decide on behalf of CLM programs which sites to monitor and which indicators should be included in surveys. We need donors to stand with us in adhering to, and communicating to governments, the principle of data ownership by CLM projects[15], 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[16].

Furthermore, in the cases where organized communities are not yet established, investment should focus on enabling the environment in which CLM could have a chance of being developed and succeed. CLM interventions cannot be fast-tracked on the expense of essential work of community mobilization where community networks to do CLM don't exist.

Issue 2: Lack of adequately funding CLM programs and delivering on-time disbursements of funds.

Funding levels for CLM projects must be adequate and predictable to enable programs to implement the full cycle of CLM activities, including developing community governance structures, support core cost for the host organization, conduct trainings and community consultations, defining and evolving indicators and data collection tools, gathering data and developing a database including electronic tools and secure storage for data collection, staffing for data analysis, pay for data collectors and advocates, conducting feedback activities at clinics, and conducting advocacy activities, including regular meetings and development of advocacy material and activities of community education, communication and advocacy.

Issue 3: Inefficient funding mechanisms with unclear implementing modalities (that often create divisions in civil society) leading to delayed disbursements and slow CLM roll-out.

Donors should commit to prioritizing financing and implementation mechanisms that ensure on-time disbursements of funding to CLM implementers. This include reducing the number of organizations that funding passes through, including by expanding opportunities for local organizations to receive funds directly or through more direct mechanisms.

Donors need to fund community organizations directly for CLM. Where this is not possible, 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/consortium proposals detailing the

[15] UNAIDS. Frequently asked questions: Community-led monitoring. 2021.
[16] CLAW. Conflict of Interest in Community-led Monitoring programs. 2021.

coordination, funding, and inclusion structures should be preferred. 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 prioritised. We recommend a more coordinated CLM donor and technical agency approach through funding mechanisms that pool resources from multiple donors.

Issue 4: Requiring impact evaluation as a measure of success at this nascent stage of global rollout is not realistic nor justified.

It is premature to ask for rapid impact assessments of CLM, even if early results are seen in a few 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 a progress assessment approaches that could be defined and measured, bearing in mind significant variations in context.

CLM goals are require engagement over time. CLM implementers are not in control of whether the services being monitored actually improve - those responsibilities lie with the ministries of health and donor-funded programmatic implementing partners that are often the targets of CLM advocacy.

We call for a CLM roadmap, clearly articulating the vision and commitment of donors to ensure a coordinated and successful implementation of these commitments, developed in partnership with CLM implementers and communities.

We urge the donor community and technical agencies to engage in a longer-term process of implementer and community engagement to identify the needs and opportunities to strengthen CLM programmes. We recognize the importance of this meeting as a key step toward developing a community-led and actionable plan for COP22, NFM4, and beyond.

Sincerely,

The Advocacy Core Team (Zimbabwe)
amFAR (US/Global)
APCASO (Asia-Pacific region)
Asia Pacific Coalition for Men's Sexual Health (APCOM)
ATAC (Ukraine)
Caribbean Vulnerable Communities (CVC) (Caribbean region)
EANNASO (Tanzania)
Eurasian Coalition on Health, Rights, Gender and Sexual Diversity (ECOM - EEAC region)
Global Coalition of TB Advocates (GCTA)
Health GAP (US/Global)

Impact Santé Afrique and the Civil Society for Malaria Elimination (CS4M)
ITPC EECA (Eastern Europe and Central Asia)
ITPC Global (South Africa/Global)
ITPC West Africa (West and Central Africa)
MPact Global Action for Gay Men's Health and Rights (MPact)
The O'Neill Institute for National and Global Health Law (US/Global)
Treatment Action Campaign (South Africa/Global)

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Annex:

Lessons learned from supporting CLM programmes

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 **EANNASO-ATAC-APCASO consortium** delivers support for CLM initiation and implementation in Tanzania, India, Cameroon, Kenya, Côte d'Ivoire, Philippines, Bangladesh.
- The **CD4C consortium**, composed of ITPC Global, MPact Global Action for Gay Men's Health and Rights (MPact), Asia Pacific Coalition for Men's Sexual Health (APCOM), Caribbean Vulnerable Communities (CVC), Eurasian Coalition on Health, Rights, Gender and Sexual Diversity(ECOM), Impact Santé Afrique and the Civil Society for Malaria Elimination (CS4M), Global Coalition of TB Advocates (GCTA), ITPC EECA & ITPC WCA, provides support for CLM programmes in Benin, Belarus, Botswana, Central African Republic, Cote d'Ivoire, Egypt, Jamaica, Kenya, Myanmar, Mozambique, the Latin America and Carribean region, Malawi, Namibia, Nigeria, Pakistan, Democratic Republic of Congo (DRC), Russia, Rwanda, Senegal, South Africa, Sierra Leone, Togo, and Ukraine.
- The **CLAW consortium**, which includes Advocacy Core Team in Zimbabwe, amfAR, Health GAP, the O'Neill Institute at Georgetown University, and the Treatment Action Campaign, provides or has provided support for CLM programs in Cameroon, Haiti, Kenya, the LAC region, Laos, Lesotho, Liberia, Malawi, Mozambique, South Africa, Tanzania, Uganda, and Zimbabwe.

Additionally, 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 programs and the development of resources and tools on CLM implementation. These resources

complement a large body of past work on CLM, including from UNAIDS[17], ITPC[18], EANNASO[19], and CLAW[20] .

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

- In Malawi's 2022 Country Operational Planning (COP) process for PEPFAR programs, CLM data was used to advocate for increased funding for viral load testing, including for additional sites and to reduce turnaround time to up to 14 days.[21]
- In South Africa, advocates have used CLM data to secure 1,285 commitments to address gaps in healthcare delivery from facility managers in 391 clinics. These commitments have contributed to large improvements in access to PrEP and GeneXpert testing, improvements in measures of treatment literacy and viral load testing, improved privacy and confidentiality, larger scale provision of DTG-containing ARV regimens, reductions in treatment gaps due to stock-outs and shortages, better infection control for airborne illnesses, improvements in staff attitudes, better weekend hours, and reduced time spent in clinics.
- In Sierra Leone, NETHIPS CLM field researchers collected data on the number of people living with HIV who experienced ART treatment failure during COVID-19, realized this data was not being captured in health center registers, and later secured a commitment by the National AIDS Control Program (NACP) to establish a new national indicator to capture such treatment failures.
- In India, GCTA CLM field researchers in New Delhi identified a significant drop in the number of TB diagnoses at the TB Alert India Designated Microscopy Center in Burari: from 100-150 per day before the COVID-19 pandemic, to 20-25 in Q4 of 2020. In-depth interviews revealed that the August 2020 guidance on bidirectional screening of TB and COVID-19 from the Indian Ministry of Health and Family Welfare was being misinterpreted, and that patients were being required to undergo mandatory COVID-19 screening before TB testing – dialogues were held to address the misinterpretation, and mandatory COVID-19 testing was addressed as a barrier to access.

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[17] UNAIDS. Establishing community-led monitoring of HIV services.

[18] ITPC. http://clm.itpcglobal.org/download/itpc-clm-community-toolkit-eng.pdf

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

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

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