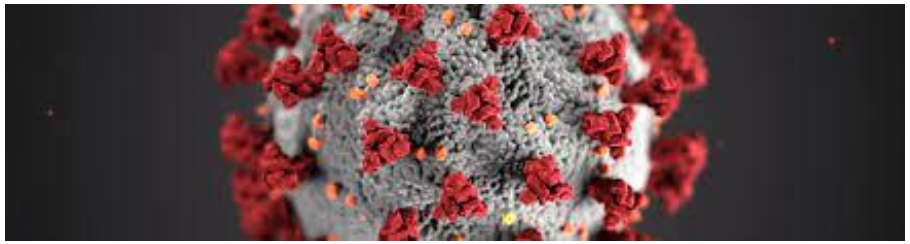
Community-led Monitoring for HIV, TB and Malaria programs and to address the impacts of COVID-19

CEECA regional webinar

07 December 2021

What is Community-led Monitoring?

The Global Fund **defines CLM** in the CSS Technical Brief (2019) as “models or mechanisms by which service users and/or local communities gather, analyze and use information on an ongoing basis to improve access to, quality and impact of services, and to hold service providers and decision makers to account.”



CLM **provides continuous feedback and data on**:

- The reality on the ground for communities when they try to access health services;
- Disruptions to HTM programs due to C19 control and containment measures;
- Document human rights violations and issues with service providers i.e., S&D in the context of COVID-19;
- Real-time feedback to decision-makers to rapidly remedy bottlenecks for more impactful disease responses.

Global Fund Approach to CLM

4.1 Summary of community systems strengthening priorities

Whilst the Global Fund recognizes that a wide range of community systems strengthening interventions can play an important role in a country's response to HIV, TB and malaria, as well as health in general, the Global Fund prioritizes funding for the following interventions:

Priority community systems strengthening interventions
Global Fund's 2020-22 allocation cycle

Component of Modular Framework	Module of Component	Interventions in Module
Resilient and Sustainable Systems for Health	Community Systems Strengthening	Community-based monitoring
		Community-led advocacy and research
		Social mobilization, building community linkages and coordination
		Institutional capacity building, planning and leadership development

Description of priority community systems strengthening interventions
Global Fund's 2020-22 allocation cycle

Intervention: Community-based monitoring

Description

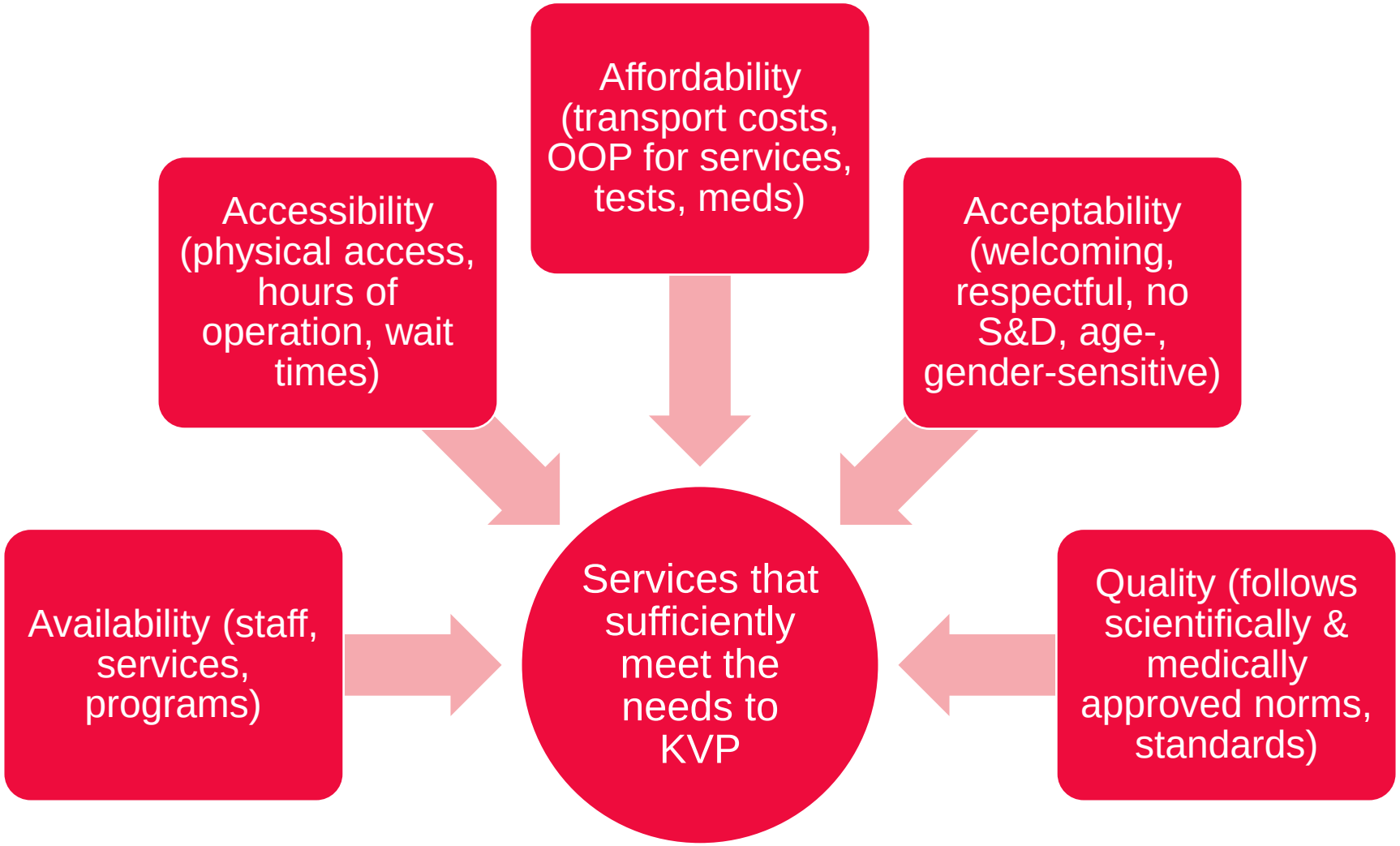
Community-based mechanisms by which service users and/or local communities gather, analyze and use information on an ongoing basis to improve access to, quality and impact of services, and to hold service providers and decision makers to account.

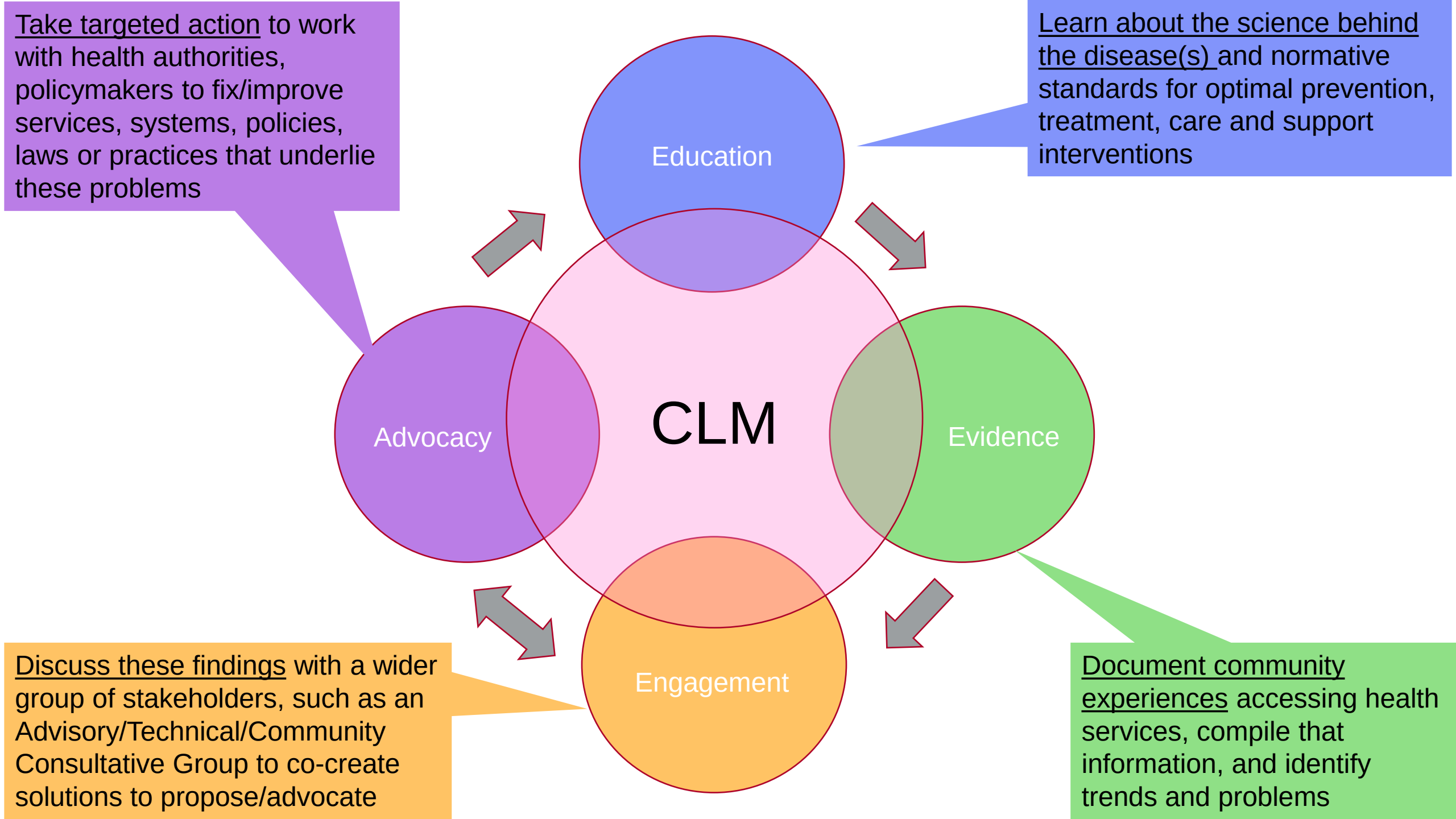
(Note: community-based monitoring is not the same as routine program monitoring).

Activities can include:

- ✓ Development, support and strengthening of community-based mechanisms that monitor: availability, accessibility, acceptability and quality of services (e.g. observatories, alert systems, scorecards); health policy, budget and resource tracking, and monitoring of health financing allocation decisions; and/or complaint and grievance mechanisms.
- ✓ Community-based monitoring of barriers to accessing services (e.g. human rights violations, including stigma and discrimination and confidentiality; age and gender-based inequities; geographical and other barriers) for purposes of emergency response, redress, research and/or advocacy to improve programs and policies.
- ✓ Tools and equipment for community-based monitoring (including appropriate technologies).
- ✓ Technical support and training on community-based monitoring: collection, collation, cleaning and analysis of data; and using community data to inform programmatic decision making and advocacy for social accountability and policy development.
- ✓ Community engagement and representation in relevant governance and oversight mechanisms.

What are we monitoring in CLM?




Take targeted action to work with health authorities, policymakers to fix/improve services, systems, policies, laws or practices that underlie these problems
Learn about the science behind the disease(s) and normative standards for optimal prevention, treatment, care and support interventions
Education
Advocacy
CLM
Evidence
Engagement
Discuss these findings with a wider group of stakeholders, such as an Advisory/Technical/Community Consultative Group to co-create solutions to propose/advocate
Document community experiences accessing health services, compile that information, and identify trends and problems

There remains confusion of what CLM is and what it is not

What CLM IS NOT	What CLM IS
Focused on priorities defined by external stakeholders (donors, governments, research institutions)	Focused on community priorities
One-time survey or report, a single “snapshot”	Recurring, routine feedback
Resulting data is published but “sits on a shelve” – data collection is the ‘end point’	Data and feedback obtained is used to advocate for change and accountability. The end goal is to find solutions that improve the lived experiences of service users accessing health services. data collection is just one step in that whole process.
Rigid definition of what kind of data “counts” and “doesn’t count” that tends to favor quantitative data and dismiss qualitative data as ‘anecdotal evidence’; priority given to epidemiological trends (prevalence rates, testing targets) with little interest in the lived experiences that underlie those numbers	Feedback can be measured by numbers (quantitative) and by people’s descriptions of their lived experiences (qualitative). It is imperative to ensure that both types of feedback and data actively informs decision making alongside facility and national data sets.
Routine M&E data collection by national disease programs/ministries. This includes collection of program data from civil society and communities engaged in project implementation.	Communities design, implement and carry out routine, ongoing monitoring of the quality and accessibility of services that they receive through disease programs.

Impact of CLM on HTM and COVID-19 Programs

VL suppression increased from 48% to 77%

Across 11 countries in WA, viral load suppression improved from 48% to 77% in less than two years of CLM implementation[1]

757 cases referred for legal support

In Kenya, advocates used CLM to collect evidence on barriers to accessing health services, and successfully referred 757 cases for legal support to a network of pro bono lawyers or to the HIV Tribunal[2]

TB medicine stockouts reduced from 95% to 5%

In the Democratic Republic of the Congo, TB medication stock-outs were drastically reduced from 95% at the beginning of 2019 to 5% in December 2019, thanks to a CLM Observatory on the Quality of Care for HIV/TB[3]

In **Sierra Leone**

- CLM data from September to November 2020 showed how GeneXpert machines were being overwhelmed by COVID-19 testing, which resulted in TB being deprioritized by healthcare workers and laboratories.
  - **RESULT: Using this data to reinforce advocacy messages in partnership with Stop TB called government to leverage testing platforms for both C19 and TB.**

- Age-disaggregated data from CLM revealed that one third of people on ART who were LTFU were young people.
  - **RESULT: Adolescents lost to follow-up strategy created to retain them using text messaging and other social media platforms to track and trace LTFU and bring them into care**

1. Regional Community Treatment Observatory in West Africa (RCTO-WA), implemented by ITPC and 11 civil society partners, found that the rate of viral load suppression improved, rose from 48.4% in January-June 2018 to 77.4% during period three the following year. Source: *Towards a Common Understanding of Community Based Monitoring and Advocacy. The Global Fund. February 2020.* https://www.theglobalfund.org/media/9632/crs_2020-02cbmmeeting_report_en.pdf?u=637319005551530000
2. The Kenya National HIV, TB and Human Rights Training and Advocacy Country Programme, implemented over a two-year period by Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN) in collaboration with local partners, across five counties in Kenya. Source: *Towards a Common Understanding of Community Based Monitoring and Advocacy. The Global Fund. February 2020.* https://www.theglobalfund.org/media/9632/crs_2020-02cbmmeeting_report_en.pdf?u=637319005551530000
3. *Implementation by Coalition of People Living with HIV Organizations (UCOP+) across 3 provinces in DRC.* Source: *Towards a Common Understanding of Community Based Monitoring and Advocacy. The Global Fund. February 2020.* https://www.theglobalfund.org/media/9632/crs_2020-02cbmmeeting_report_en.pdf?u=637319005551530000

Tips and Technical Notes

For planning, strengthening your CLM program

- **CLM is community-centered**. The community chooses their own indicators of what to monitor and where to work, prioritizing those things that matter most to them (centred around the AAAAQ)
- **CLM is independent from national M&E.** National CLM strategies are useful to understand which CLM implementer is collecting which data, where and for which populations and how CLM data is shared/fed back to the program, but it is not an extension of a national disease program and should not be coordinated by the govt.
- **CLM should be implemented by affected community organizations.** This is sometimes confused with CSOs/NGOs providing services or umbrella CSO platforms.
- **CLM uses quantitative and qualitative indicators** to provide a full picture of the issues to inform advocacy and monitor progress.
  - Quantitative data (e.g. # of patients who visited a clinic to access malaria prevention treatment, or # of PLHIV who frequented an ART distribution point)
  - Qualitative data to document a person's lived experience (e.g., "Ever since the drop-in center closed, I have felt isolated"; "COVID-19 lockdown measures have made it difficult to avoid my aggressor"; "I didn't go for a VLT because I don't know why it's important").
- **CLM data is only useful if it is used and fed back to facility managers, program managers, decision-makers, policymakers and discussed to find solutions to issues identified**
- **CLM is not a "one hit wonder" as monitoring is an on-going activity**.
  - Data is collected monthly or quarterly and analyzed for trends (e.g., "clinic attendance has dropped 37% over the last three months" is a more useful piece of information than a one-time snapshot, i.e., "467 patients attended the clinic this month")
- **The point of CLM is not just to collect data, but to use the data to FIX PROBLEMS**. Many tools available to collect data, but coordinating data sharing among CLM implementers and collectively strategizing on use of data still needs work.

CLM for C19RM investment
TA opportunity

Phase 1: September 2021 – February 2022

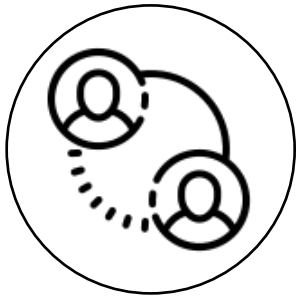
Phase 2: March 2022 – December 2023

What does this investment look like:
Core components to strengthen community-led monitoring in C19RM

RAPID IDENTIFICATION OF IMPACT OF COVID-19

Objective 1: Understand the impact on people living with and impacted by HIV, TB, and malaria (HTM), and work to make adjustments in real-time to ensure ongoing access by **strengthening the technical capacity of communities to gather, analyze and use granular data** on availability, accessibility, acceptability, affordability and quality of HIV, TB, malaria and COVID-19 prevention and treatment services**,** increasing the technical rigor of CLM models and improving the impact of C19 and HTM programs through advocacy shaped by CLM evidence.

Outcome: CLM is adequately resourced, implemented with fidelity in 70 CLM interventions



CLM ACTIVELY INFORMS COVID-19 + HTM RESPONSES

Objective 2: Strengthen **integration of CLM into COVID-19 disease responses** and improve linkages to national strategies social accountability, particularly around human rights and gender-based violence, as well as improved global coordination on COVID-related community-led monitoring efforts, in order to improve program quality; along with increased resources invested in community systems and responses to improve program performance and equity, oversight, and accountability.

Outcome: CLM actively informs COVID-19 strategies and HTM disease responses

EVIDENCE AND LEARNING

Objective 3: Generate evidence on the impact of CLM on C19RM funding priorities, collaborating with technical partners, donors and communities to capture best practice approaches, and contribute to the global body of knowledge as well as regional communities of practice.

Outcome: Accessible resources to quickly identify and respond to issues, generate evidence on impact, document best practices, provide guidance

What types of TA are supported under the CLM C19RM TA?

Main TA areas of support	Menu of TA activities
1. Strengthen the capacity of communities to gather, analyze and use data for improved availability, accessibility, acceptability and affordability of HIV, TB and malaria services in the context of Covid-19	__ CLM strategy development (including indicator selection, site selection, determining CLM mechanisms and structures) __ CLM protocols and tool development (such as community scorecards, patient satisfaction surveys, resource and budget tracking tools) __ Data triangulation and verification exercises __ CLM database development including software/digitalization __ In-person/virtual training and mentorship on data collection processes, analysis, reporting __ Data quality audits or other quality assurance processes
2. Integrate CLM in national C19 responses	__ Developing national and local level multi-sectoral partnership plans for sharing data for decision making to increase/improve services and quality __ Communication protocols including establishing bi-directional “feedback loops” to ensure data quickly reaches decision-makers who can use the data to adjust program strategy __ Organizing evidence-sharing meetings with communities and other stakeholders __ Participation in national and local level meetings where CLM data can be shared
3. Advocacy strategy and implementation	__ Improve/establish CLM advocacy strategies __ Development of advocacy materials based on CLM data __ Organizing advocacy planning and strategy sessions to use CLM data __ Organizing and conducting training sessions on using CLM data for advocacy
4. Document impact of CLM on C19RM funding priorities	__ Developing written case studies on effectiveness and/or outcomes of CLM interventions for public dissemination – including abstracts for conferences, articles for journals, other materials development.

CLM C19RM Short-term TA opportunity – Phase 1 just closed on November 15

A variety of groups can request TA, including:

- Civil society organization (CSO)
- Community-based organization (CBO)
- Key population network or organization
- Faith-based organization (FBO)
- Youth organization
- Government / government department
- Public health facility
- Private sector health facility or service site
- Global Fund PRs and SRs
- Global Fund Country Teams

KEY RESOURCES: (English, French, Spanish, Russian)

- CLM C19RM Short-Term TA Guidance note for Applicants
- CLM 19RM TA Request Form

Phase 1 Eligibility Criteria:

1. *CLM interventions are budgeted in C1RM grant (or in core HTM grants for C19 adaptations)*
2. *TA objective is clear and fits within the scope of TA activities available*
3. *There is existing CLM in the country for the TA to support/build on*
4. *The TA request is not duplicative of a TA request to another funder (e.g. UNAIDS, PEPFAR, STB, etc.)*

Phase 1:

Short-term TA: **20-40 days**

Approx budget per assignment: **USD 25,000**

Implementation timeframe: ***JUST CLOSED / Nov 2021–Feb 2022***

Submission deadline for Phase 2 TBD

Prioritized requests following review –

Belarus (People Plus), Russia (HIV coordinating committee), Ukraine (Positive Women), Moldova (Positive Initiative)

Approved GF CLM TA providers

THREE CLM community consortiums selected via competitive process for disease expertise, regional presence, language proficiency, etc.

- **Community-Led Accountability Working Group (CLAW**) led by Health Gap and Asia Catalyst with Treatment Action Campaign South Africa (TAC), Advocacy Core Team (ACT) of Zimbabwe, the Public Policy Office of amfAR, O'Neill Institute for National and Global Health Law at Georgetown University.

- **Eastern Africa National Networks of AIDS and Health Service Organizations (EANNASO)** with APCASO and Alliance for Public Health Ukraine.

- **Community Data for Change Consortium (CD4C**) led by ITPC Global and MPact with AMSHeR, APCOM, Caribbean Vulnerable Communities (CVC), Eurasian Coalition on Health, Rights, Gender and Sexual Diversity (ECOM), Global Coalition of TB Activists (GCTA), ITPC EECA and ITPC WCA.

Useful CLM Resources, Guides, Tools

- The Global Fund's 2019 *Technical Brief on Community Systems Strengthening*
- The Global Fund's May 2020 *Community-based Monitoring: An Overview*
- The Global Fund's Feb 2020 *Towards a Common Understanding of Community-based Monitoring and Advocacy*
- *Towards a Common Understanding of Community-based Monitoring and Advocacy*, Meeting Report, Joep Lange Institute, 2020.
- Baptiste et al, *Community-Led Monitoring: When Community Data Drives Implementation Strategies*. Current HIV/AIDS Reports, 2020.
- The Global Fund *Community Engagement video*
- UNAIDS 2021 *Establishing community-led monitoring of HIV services*
- PEPFAR 2020 *Fact Sheet: Community-led Monitoring*
- PEPFAR Solutions Platform 2020 *Community-led Monitoring Tools*
- ITPC *Community Treatment Observatory (CTO)* model, tools, findings from 11-country West Africa project
- Health Gap *Ritshidze model*
- Frontline AIDS *REAct (Rights-Evidence-Action)* HRV monitoring
- Stop TB Partnership *OneImpact app*

Thank You

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Education

Learn about the science behind the disease(s) and normative standards for optimal prevention, treatment, care and support interventions

Conduct interactive treatment education and capacity-building with community members to gain a working scientific knowledge of HIV, COVID-19, and TB, as well as their rights.

Communities need to understand what they are monitoring: what to collect, why to collect it, and how it will be used.

Cost Considerations

- **Situational analysis:** Identify any existing CLM efforts and/or identify known issues to build upon in inception meetings
- **Health and legal literacy:** Empowering communities with knowledge of their health and human rights
- **Training curriculum:** Write and publish training toolkit, hire meeting facilitator or trainer, provide internet access for participants
- **Supplies:** stationery and pens, flip charts
- **PPE:** hand sanitizer, masks
- **Staffing costs:** Focal point, data supervisors, M&E lead
- **Core support for lead CLM organization:** Overhead, administrative fees, part-time finance and programmatic support.

Evidence

Document their experiences accessing health services, compile that information, and identify trends and problems

Define scope of CLM: Identify priority monitoring issues and develop indicator framework to include disease specific and COVID-19 sensitive indicators. Which of the 5 A's would be your focus? What is the problem you want to address?

Data collection and management: Develop data collection tools to capture data and disaggregate in the indicator framework.

Pilot data collection tools and gather baseline data. The data management process should include data verification, quality assurance procedures, and routine review of data.

Data analysis: Conduct routine review of data to analyze trends, comparing pre-COVID data and current monthly trends where available, identify bottlenecks, and identify successes from review of data and analysis.

Cost Considerations

- **Staffing costs:** Equipment
- **Data management costs**
- **Fees to secure ethical approvals and implement privacy and safety protocols**
- **Training:** data team, data collectors
- **Monthly focus group meetings** for qualitative data collection, voice recorders, monthly supervisory visits
- **Core support for the organization implementing CLM**

Engagement

Discuss these findings with a wider group of stakeholders, such as a Community Consultative Group (CCG) or existing proxy, to co-create solutions

Convene regular meetings (monthly or quarterly) through a multi-stakeholder engagement process such as a Community Consultative Group (CCG) or existing group to co-create solutions, such as a CCM or C19 Response Task Team.

Include representatives from national PLHIV networks, TB survivors, malaria initiatives, key population groups, healthcare facilities, service users, public health and HIV experts, program managers, policymakers, and academic partners.

Cost Considerations

- **Support for CCG convenings:** transport, meeting costs, facilitation, printed materials, audio-visuals – biannually at national level; quarterly at district level
- **Writing and disseminating quarterly reports**
- **Core support to CLM host organization**
- **Monitoring engagement and creating advocacy logs**

Advocacy

Take targeted action to work with policymakers to fix or improve the services, systems, policies, laws or practices that underlie these problems

Meetings with relevant decision/policymakers to co-create solutions when data collection reveals gaps in access to and quality of services, stockouts, human rights issues, and other problems.

Hold decision-makers to account as needed.

Push for implementation of the solutions co-created above if progress is lacking.

Cost Considerations

- **Support for policy analysis and advocacy campaign design and development**
- **Meetings with policymakers on advocacy issues at national, district, and community levels**
- **Core support for CLM host organization**
- **Maintaining advocacy logs**

Results from CLM adaptations in Sierra Leone

From identification of issues to proposing solutions, civil society advocacy led to the impactful results

Issues

- Viral load machine was not working
- Capture treatment failure in service registers
- Address stock-out at health facilities
- Address factors leading to lost to follow up

Proposed Solutions

- Engage key partners to repair/replace viral load machine
- Engage NACP to capture treatment failure in service registers
- Adopt a national strategy that addresses stock –out
- Effective roll-out DSD and adopt task shifting at health facilities

Advocacy Messages

- Viral load machine repaired or replaced
- Treatment failure captured in service registers
- National strategy or pathway adopted to address stockout
- DSD rolled-out to address lost to follow up issues

Result

- Viral load machine has been fixed and will commence operation soon
- Received commitment from NACP to include treatment failure as indicator when national tools are reviewed