Integrating Community-Led Monitoring (CLM) into C19RM Funding Requests

> " 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."

Introduction & Purpose

In April 2021, The Global Fund to Fight AIDS, TB and Malaria (The Global Fund) launched the second phase of the COVID-19 Response Mechanism (C19RM), which prioritizes a range of initiatives to better understand and mitigate the impact of COVID-19 on people affected by the three diseases – including via support for community-led monitoring (CLM) interventions.

Eligible investments for C19RM are:
1. COVID-19 control and containment interventions, such as testing and treatment, provision of personal protective equipment (PPE), communications and other public health and social measures (PHSM);
2. Activities to mitigate the effects of the COVID-19 pandemic on HIV, TB, and malaria; and
3. Expanded reinforcement of key aspects of health and community systems.

For more information about the C19RM process, application window deadlines, and how to apply, please refer to this community update on C19RM

All countries receiving funding from the Global Fund are eligible to receive C19RM funding, including multi-country and non-eligible countries in crisis.

Integrating community-led monitoring into C19RM will save lives

As the COVID-19 pandemic continues to challenge, and in some cases overwhelm health services, we must urgently take action to 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 to, and uptake of prevention, treatment, care and support services. **Community-led monitoring (CLM)** is a powerful tool that rapidly generates granular data regarding the accessibility and quality of HTM prevention and treatment services (i.e. service disruptions, poor quality services, commodity stockouts, and human rights and gender-related barriers), and empowers communities to use CLM findings to identify and advocate for solutions.

Concrete examples of what CLM has achieved to date include:

- Viral load suppression improved from 48% to 77% across 11 countries in less than two years of CLM implementation.[1]

- 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]
- 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.

The purpose of the brief

The purpose of this brief is to define community-led monitoring, to explain the value of integrating CLM into funding requests to the Global Fund's current C19RM, to provide a short overview of how CLM should be programmed and costed, to share tips to ensure that CLM is properly included in your upcoming C19RM funding request, and to share case studies of CLM in the context of COVID-19.

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[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, rising 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

What is community-led monitoring (CLM)?

Community-led monitoring in simple terms

Community-led monitoring is defined as a process where communities, particularly health service users, take the lead to routinely monitor an issue that matters to them - by identifying their top priorities; creating indicators to track those priorities; collecting data; analyzing the results; and sharing insights from the data with a larger group of stakeholders. Communities then work alongside policymakers to co-create solutions to the problems they have identified (you can learn more about how to design and plan CLM later in this brief). When problems uncovered through CLM cannot be resolved, communities engage in evidence-based advocacy and campaigning until they achieve implementation of corrective actions by duty bearers. Please refer to the appendix for a series of institutional definitions of CLM.

CLM is not a new idea. For decades, communities across the HTM movements have worked together to identify issues impacting their health and to bring action to bear on decision-makers. What is new, however, is greater recognition by donors and program implementers of the value that community-generated data and advocacy bring to program impact. As a result, CLM is now a funded priority.

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 data collection
• Resulting data is published but "sits on a shelf" – data collection is the 'end point'	• Data obtained is used to advocate for change. 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	• Data can be measured by numbers (quantitative) and by people's descriptions of their lived experiences (qualitative)

"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."

Baptiste, S., Manouan, A., Garcia, P. et al. Community-Led Monitoring: When Community Data Drives Implementation Strategies. Curr HIV/AIDS Rep 17, 415–421 (2020). https://doi.org/10.1007/s11904-020-00521-2

What is the value of CLM in the current context of COVID-19?

Community-led monitoring optimizes program impact. Without it, HIV, TB, and malaria programs will be severely hampered; with it, HTM programs can succeed, even in the unpredictable context of COVID-19.

Communities have a unique ability to accurately document the lived experiences of people impacted by HIV, TB and malaria; to identify emerging issues; and to recommend appropriate solutions. CLM reinforces the importance of community pandemic preparedness, and reveals how empowered communities can play a pivotal role in supporting the continuity of quality services by holding policymakers accountable.

The specific **benefits of integrating CLM into C19RM** requests include:

- Rapid issue identification: Advocates have used CLM effectively to track disruptions to HIV, TB, and malaria programs due to the impact of COVID-19 (lockdowns, shortages of personal supplies of life-saving medicines, reduced mobility, closed clinics, cessation of community-based services, cessation of in-person support groups and drop-in centers). In a five-country study, CLM identified the following issues:

  - Decreases in same-day antiretroviral   therapy (ART) initiation
  - Loss-to-follow-up, particularly for young people
  - Rising stigma
  - Rising TB diagnostic waiting times because of the reprioritization of Gene eXpert machines for COVID-19 diagnostics.
  - In three countries, communities developed a combination of remote snap surveys and " COVID-19-safe" CLM protocols demonstrating how networks can adapt to COVID-19 out breaks to carry out CLM safely while capturing real time information about the effect of COVID-19 on communities.

- Real-time problem solving and accountability to communities. CLM brings together multiple stakeholders to both identify programmatic and systematic priorities – and to advocate for swift implementation of solutions – which ultimately leads to improved quality of services, program performance and health outcomes.

- Improved treatment outcomes: Use of CLM in a regional community treatment observatory project in West Africa resulted in increased viral load suppression from 48% to 77%.

- Transformative power to strengthen data, and by extension, community and health systems: CLM generates high-quality data that heretofore has been missing, preventing governments from solving urgent problems. CLM data is used to identify opportunities for strengthening community and formal health systems, pinpointing specific changes to ensure their resilience in the face of the concurrent pandemics of HIV, TB, malaria, and COVID-19.

- Improved gender and human rights outcomes. The CLM model can be applied not just to disease programs, but also to monitor trends in social and structural health interventions, such as gender-based violence, food insecurity, sexual and reproductive health, and the promotion and protection of human rights. In one country, CLM was used to track the effects of lockdowns on economic and food insecurity among vulnerable communities, particularly pregnant people and children with HIV and their caregivers. These data were used to advocate with policymakers to expand investments in emergency COVID-19 assistance.

> **"The community sector holds the key to critical data and information that governments may not have, or are unwilling to report on, particularly concerning the needs and challenges faced by key populations, those marginalized and most at risk. Community groups can bring to the table relevant and updated information that will present a more realistic picture of the country's pandemic status."**

Source: APCASO Global Fund COVID-19 Response Mechanism (C19RM)

Civil society entry points to integrate CLM in C19RM applications

The C19RM follows similar steps to the HIV, TB, malaria and RSSH Global Fund funding application process which requires meaningful engagement of civil society and communities throughout: from the funding request development to grant making and grant implementation and oversight. The Global Fund recognizes the importance of integrating community-led monitoring in its programs to catalyze grant performance.

Global Fund C19RM Guidance Note explicitly calls for civil society engagement:

- "For the C19RM Full Funding Request, effective community and civil society engagement are crucial for developing a robust response to the pandemic, including opportunities to support community-led initiatives, to both mitigate the impact on HIV, TB and malaria services, and strengthen the national COVID-19 response."

- "Applicants must consult with, at minimum the HIV, TB and malaria national control programs, civil society, key and vulnerable populations as well as communities, including those most severely affected by COVID-19. This includes CCM members and non-CCM representatives. Even if a country is experiencing significant disruption, CCMs are still expected to make efforts to invite inputs from civil society, communities and key populations using virtual tools."

Source: https://www.theglobalfund.org/media/10759/covid19_c19rm-guidelines_external_en.pdf

Where to raise your voice
Opportunities to ensure community-led monitoring is included in C19RM funding requests:

- **National COVID-19 task team forums:** These are composed of representatives from the public sector, the private sector, and civil society, representing HIV, TB, malaria and other affiliated health areas. They provide a unique entry point for integrating CLM mechanisms into COVID-19. During task team meetings, a country's response is evaluated to identify gaps and barriers. Recommendations can include establishing or strengthening CLM to fill in the gaps. Information generated from CLM should be presented by communities and reviewed and used as appropriate during task team meetings as a critical data source that can inform the national COVID-19 response.

- **National COVID-19 dialogues and priority setting forums:** These are crucial platforms for civil society and communities to participate in national priority setting meetings. It gives them an opportunity to provide feedback and articulate the importance of CLM as a building block of community systems, which is an integral component of national healthcare systems.

- **C19RM funding request:** Stakeholders, including civil society and communities, should clearly articulate CLM interventions as a topline priority in the C19RM funding request base allocation (not as and prioritized above-base allocation request, or PAAR) and ensure that they participate in the work planning and budgeting process to ensure CLM is adequately resourced.

- **CCM oversight:** Civil society and community representatives on the CCM are strongly encouraged to advocate for adequate funding allocation to CLM mechanisms and safeguard the same during COVID-19 grant implementation.

*For more details on specific questions to ask, please refer to the Appendix: "**Key entry points for engaging on CLM throughout the C19RM process and reflection questions**."*

What to ask for
Where to champion community-led monitoring within C19RM

- Strengthening Resilient & Sustainable Systems for Health (RSSH): It is important for civil society and communities to dialogue within their constituencies on the value of CLM - specifically, improved accountability - as fundamental to strengthening community systems as part of building resilient and sustainable systems for health. Reinforce the importance of short feedback loops and unique perspectives of service users that strengthen RSSH as a result of CLM.

- Civil society and communities should ensure that their respective disease-specific national strategies include explicit recommendations on Community Systems Strengthening (CSS), including on the need for CLM during the ongoing COVID-19 pandemic to mitigate disruption to services and to ensure accountability for effective and equitable HIV, TB, malaria and Covid-19 program delivery.

- Stakeholders, including civil society and communities, must ensure that the implementation arrangements developed include community-led organizations as implementers of CLM mechanisms, and that detailed work plans and budgets adequately fund all components of the defined CLM mechanisms. CLM should always be implemented to ensure its independence from donors and governments.

The Global Fund's Policy Mandate for Including CLM in C19RM Funding Requests

The Global Fund has made clear that it is imperative to include CLM as a core component of C19RM Funding requests. ***Please refer to the Appendix to see how the Global Fund Board explicitly states why CLM is needed, and how it fits into the C19RM funding request process.***

The funding mandate for CLM within C19RM
All funding requests for C19RM need to fall within the mechanism's three categories, and map against each country's National Strategic Preparedness and Response Plan for COVID-19 (NSPRP), which has 10 Pillars. The Global Fund's Technical Information Note clarifies where CLM falls in this matrix, as summarized in the table below.

Three Buckets of Eligible Investments under C19RM	Where CLM falls among relevant NSPRP Pillars in this bucket
• COVID-19 control and containment interventions, such as testing and treatment, provision of personal protective equipment (PPE), communications and other public health and social measures (PHSM)	**Country-level co-ordination and planning (Pillar 1)** Support civil society and community organizations to enable them to play a meaningful part in country-level coordination. **Risk communication and community engagement (Pillar 2)** Identify and map marginalized and at-risk populations to engage with culturally appropriate messages using relevant channels and community networks. Establish mechanisms to embed the voice of communities into decision-making for emergency responses.
• Activities to mitigate the effects of the COVID-19 pandemic on HIV, TB and malaria	**Mitigation for disease programs (Pillar 9)** Support the development, adaptation, and delivery of additional services through community responses and expansion of CLM.
• Expanded reinforcement of key aspects of health and community systems	**Cross-cutting interventions (not specific to any pillar)** related to resilient and sustainable systems for health (RSSH), including: support for community-led monitoring (CLM), responding to human rights and gender related barriers to services, and institutional capacity building, among others.

How to design and plan CLM programs

For decades, communities across the globe have been pioneering monitoring and advocacy work out of life-saving necessity. Many different models and concepts have been utilized, each tailored to the specific context in which they have been implemented, each evolving to best suit the needs of the communities they serve. This brief presents the model developed by the International Treatment Preparedness Coalition (ITPC)[1] which defines CLM[2] as consisting of four critical components. [3]

In the case of HIV, TB, malaria, and COVID-19, CLM is an action undertaken by a community of people impacted by a health issue in which they take power into their own hands to:

1. Learn about the science behind the disease(s) and normative standards for optimal prevention, treatment, care and support interventions (**EDUCATION**);
2. Document their experiences accessing health services, compile that information, and identify trends and problems (**EVIDENCE**);
3. Discuss these findings with a wider group of stakeholders, such as a Community Consultative Group (CCG) or existing proxy, to co-create solutions (**ENGAGEMENT**); and
4. Take targeted action to work with policymakers to fix or improve the services, systems, policies, laws or practices that underlie these problems (**ADVOCACY**).

* The relationship between the ENGAGEMENT and ADVOCACY components is mutually reinforcing and cyclical as represented by the arrows at the bottom left of Figure 1 below.
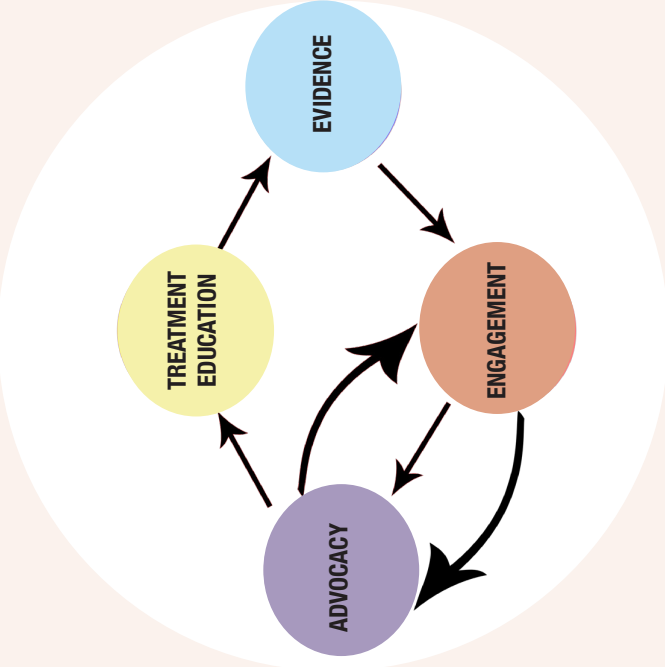
As illustrated in Figure 1, CLM is an ongoing, routine process. The cycle repeats itself in a recurring loop, usually every month or every quarter. In the context of COVID-19, it is advised that data collection occur even more frequently, depending on issue, needs, and context.

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1   *The ITPC CLM model was informed by years of work in this field with partners, including establishing a Community Treatment Observatory model that was pioneered with support from the Global Fund.*
2   *Note: Communities often use the full term "Community-Led Monitoring & Advocacy (CLM&A)" to highlight the importance of the last step – advocacy to fix problems – which is what transforms CLM from mere data collection into community-led action for change. For the purposes of this brief, we use the term "CLM" as referenced in the Global Fund's C19RM Guidance documents.*
3   *Source: ITPC: How to Implement CLM&A – A Community Toolkit*

Figure 1: The Key Components of Effective Community-led Monitoring and Advocacy

CLM Component	Details	Recommended Costing Categories (Resource considerations)
Treatment Education	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.	• Situational analysis: Identify any existing CLM efforts and/or identify known issues to build upon in inception meetings: National level, District level, Community level (transport, conference package or hall hire, facilitation, printed materials, audio-visuals, refreshments) • Training curriculum: Write and publish training toolkit, hire meeting facilitator or trainer, provide Internet access • 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	Define scope of CLM: Identify priority monitoring issues and develop indicator framework to include disease specific and COVID-19 sensitive indicators (e.g. will your activities focus on prevention, diagnosis, treatment, care or support or community systems? 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 allow for capture of the 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.	• Staffing costs: Data collectors (two staff X site; data collection recurs on a monthly or quarterly basis); Data team including data supervisor; M&E officer; focal point • Equipment: Paper, tools, tablets for data collectors, transportation for data collectors, internet/data bundle for data collectors, raincoats, laptop, bags, etc. • Data management costs: Support for organizing and systematizing the monthly reporting process. Support analysis of incoming data, including coding qualitative data. • Data platform: Hosting, access, maintenance, etc. • Fees to secure ethical approvals and implement recommended privacy and safety protocols (i.e. data management to ensure confidentiality) • Baseline assessment • Training: Data team, data collectors • Monthly focus group meetings for qualitative data collection, voice recorders, monthly supervisory visits • Core support for the organization overseeing CLM
Engagement	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.	• 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
Advocacy	The CCG or existing proxy meets 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.	• Support for policy analysis and advocacy campaign design and development • Meetings with policymakers on advocacy issues at national, district, and community levels (transport, meeting costs, printed materials) at least biannually, ideally quarterly • Core support for CLM host organization

(A) A few important technical notes:

- CLM is independent and community-centered. The community chooses their own indicators of what to monitor and where to work, prioritizing those things that matter most to them. Examples can include availability of medicines, the nature of community members' interactions with healthcare staff, user fees, quality of services, barriers to accessing services, and experiences of stigma and discrimination.

- CLM uses quantitative and qualitative indicators to provide a fuller picture of the issues to inform advocacy and to monitor progress. Data collection can take many forms. It can include quantitative data such as recording specific numbers (e.g. the number of patients who visited a clinic to access malaria prevention treatment, or who frequented an ART distribution point in a particular month), as well as qualitative data such as documenting 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 no longer have work or social activities outside of the home to give me regular opportunities to leave his presence and my risk of gender-based violence has shot up.").

- The evidence that is generated by CLM is fed back to program managers, decision-makers and policymakers, enabling them to increase the "five A's" (availability, accessibility, acceptability, affordability, and appropriateness) as well as the efficiency and effectiveness of their services.

- CLM is not a "one hit wonder" as monitoring is an on-going activity. Data is collected every month or every quarter. This makes it a powerful way to identify trends and advocate for improvement (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. The end goal is to collaboratively FIX PROBLEMS by finding solutions that improve the lived experiences of service users of health systems; data collection is but one step in that whole process. CLM enables communities to claim their right to health by pinpointing problems (e.g., service gaps, areas for improvement) and using that information to hold policymakers and healthcare systems accountable.

(B) Costing tips

» Use the table above, especially the "Recommended Costing Categories" column to sketch out your budget. The units will depend on your CLM design (i.e. multiply each costing category by the number of project sites, etc.)

» Think about the technical support you will need: costs could include technical support refresher training (refining indicators, data and process flow adjustments, Data Quality Audits or DQAs etc.); DQA at sites and feedback; on-going technical assistance or TA (technical and political); support to engage with academic institutions or consultants (for data analysis and synthesis), etc.

» EANNASO has also developed a detailed, activity-based costing guide for CLM, which can be accessed on pages 19-20 of their resource, Community-Led Monitoring: a Technical Guide for HIV, TB and Malaria Programming.

» CLM requires robust resources. A CLM implementor's experience documented covering 15 sites, in an urban setting, with two data collectors per site, for approximately US$150,000 per year. Costs can vary depending on the size, scope, and location of the project. Rural work generally requires more resources, and U.S. dollar-based cost estimates may vary depending on a given currency's exchange rate.

» Data collectors must be paid for their work. There can be a tendency to "tack on" unpaid CLM data collection responsibilities to individuals already working as outreach workers or community healthcare workers. Do not do this! Include proper remuneration for data collectors in budgets.

(C) Who should monitor

Community partners. CLM must be led by organizations that have a long-standing, trusted relationships with the communities in their respective locations to be effective.

Data collectors must be knowledgeable about the issues and credible within the community if they are going to be effective in their role.

Local organizations of people living with HIV, TB survivor groups, and/or malaria initiatives may be best placed to lead on designing and collecting data about the community's experience accessing healthcare services during COVID-19.

> Key population (KP)-led organizations are likely to be the most trusted partners to lead engagement on data collection to monitor the health and rights of KPs.

> CLM is not effective if there is a conflict of interest – for example, the provider of the health services being monitored cannot lead the CLM initiative. Mitigate conflicts of interest by ensuring that CLM funding and CLM project leadership is fully independent of the sites, services and systems being monitored.

(D) Where to monitor

From the outset, the community should identify the sites where monitoring will take place on a recurring cycle (monthly or quarterly).

» Site selection should align with the goal of the CLM (i.e. a CLM initiative seeking to account for the impact of COVID-19 on KPs should choose appropriate sites; efforts to monitor Gender Based Violence (GBV) or other human rights violations should center on those most at-risk).

» Under normal circumstance, physical spaces/sites such as hospitals, clinics, laboratories, or pharmacies are good monitoring targets. However, due to COVID-19 restrictions, virtual spaces (adherence clubs, support groups or drop-in centers that have moved into virtual meeting spaces) should also be considered as monitoring targets.

» Partners should decide whether to focus on urban or rural sites, or a mix of the two.

» Ensure you have the capacity to monitor all the sites and be realistic about what you can achieve.

» When monitoring has a disease-specific component (for example, the impact of COVID-19 on people living with HIV, TB survivors, or malaria programs), it may be strategic to focus on high-burden sites.

» Utilize disaggregation to focus in on specific areas of interest, such as age- and sex-disaggregated factors and by KPs (i.e. those sites who serve the highest density of young people, sex-workers, etc.)

(E) What to monitor

Data: The type of data collected may vary based on sites.

Provided that all ethics and privacy protocols are met, quantitative data can be collected through clinical records and/or written materials. The data therefore hinges on the number of people who access a given monitoring site and whose interactions are captured in records that can be reported out via desk review. (See below for more information on crafting indicators.)

Qualitative data is often gathered by asking key stakeholders and service users open-ended questions via interviews or focus groups and recording their answers. This may take longer to complete and analyze, and the usefulness of the data may depend on the availability of data collectors to organize and conduct this work with individuals whose lives have already been impacted by COVID-19 (healthcare workers and service users, including people living with HIV, TB survivors, and malaria programs beneficiaries).

Complementarity: One of the many strengths of CLM is the opportunity to utilize both quantitative and qualitative data to identify trends enabling a fuller picture of a complex and multifaceted issue.

For example, quantitative data from a COVID-19 CLM project led by ITPC in cities in five countries showed very low HIV testing and treatment rates implying that recipients of care faced additional barriers to due to lockdown restrictions that limited free movement. Local partners used qualitative research methods to deeply probe the impact of COVID-19 on people living with HIV, thereby exposing issues related to job loss, food insecurity, school closures, and movement restrictions. The fullness of this data gives a more holistic picture of the impact of COVID-19 across all aspects of a person's (who is living with HIV) life, beyond just the numbers being reported out of health facilities.

Ethics and privacy

- Healthcare data collection involves highly sensitive information. For example, medical records can reveal a person's HIV status and qualitative interviews can disclose personal information about sexual orientation or traumatic events, including human rights abuses. This data must be handled with the utmost care. Proper protocols to ensure privacy are vital. Prior ethical approvals should be obtained in advance to ensure that participants understand and consent to the information they are disclosing.

- Vulnerable groups (including young people and key populations) must be involved from the earliest stages in CLM design to ensure that CLM processes understand and respect their safety concerns with regard to privacy and confidentiality. Work with the KP representative on your CCM and other civil society leaders as a starting point.

- We strongly recommend that the CLM database be created and managed separately from national systems. This reinforces community ownership over the data and adds an additional layer of assurance that it will be kept safe or will not be misused.

- Data management costs can be significant, and privacy-related costs (including measures to keep data safe in a digital space) must be met in order to assure the integrity of CLM as well as to ensure legal and ethical compliance at a national-level.

(F)   Examples of CLM activities and indicators

The Global Fund's COVID-19 Response Mechanism Technical Information Note describes all the CLM activities that are eligible for support within C19RM funding requests as follows:

Community-led monitoring (p.30)

Specific activities supported under CLM 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 policies, budgets, resource tracking, and monitoring of health financing allocation decisions; and/or complaint and grievance mechanisms;
- Community-led and/or -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-led and/or -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;
- CBO monitoring of the impact of COVID-19 on health service providers in their communities; and
- Support communities to monitor and report stock-outs, quality of services and human rights violations.

CLM activities that are particularly relevant during the COVID-19 pandemic include:

- Invest in integration of community-based education and advocacy efforts to overcome diagnostic and vaccine hesitancy within ongoing activities, as appropriate;

- Invest in adherence support among people living with HIV and TB, and prevention support for malaria programs;

- Support the development of advocacy materials on the importance of preserving access to HIV, TB, and malaria services and reproductive health services, and relevant activities on monitoring and reporting on access to services;

- Invest in the use of e-Health, telemedicine tools, and virtual platforms to deliver services based on the needs of service users;

- Include direct measures of quality of care, such as wait time, perceived sufficiency of health workers, health worker attitudes.

UNAIDS has also written a helpful [CLM guidance document](#) that describes examples of topics that can be routinely evaluated through CLM, and that may not be captured elsewhere (i.e. service quality, service provision, structural and policy enablers of effective HIV responses). You can draw inspiration from their list when crafting your C19RM funding application.

Community groups should decide on the issue areas they want to monitor, based on their review of the current context, national policies, problems identified, and their own lived experiences with HIV, TB, and malaria during COVID-19. Communities should borrow from the topics listed above to ensure they are eligible for funding through the C19RM process. Next, indicators (and sources) should be identified as that will allow the issues to be tracked.

This could include reviewing existing local indicator frameworks to select key indicators *(refer to the Appendix for a sample list of quantitative and qualitative indicators for monitoring HIV in the context of COVID-19).*

What to do NOW:

● Do not wait to be asked to participate! Get in touch with your C19RM writing team without delay. Be in touch with your CCM CSO representatives for contact information and include KP issues in the discussions.

● Remind your CCM that CLM is an independent, ongoing process, not a one-off event or report. Data collection, analysis, reporting, and problem solving will take place regularly throughout the year. Community-generated CLM data is credible and should be weighted equally with information from government data systems (remember: it is vital that CLM data remain independent from government data systems).

● Watch the budget. CLM must truly be owned and led by communities, meaning that the funding for this work must go directly to community organizations. If funding for CLM flows to an institution whose work is being monitored (such as the government) it will create an unacceptable conflict of interest. Again, communities decide what should be monitored – CLM is different from Monitoring & Evaluation (M&E) and therefore requires its own budget.

● Remind any skeptical stakeholders that CLM is not solely watchdogging, and that it is much more. CLM is a collaborative process in which all stakeholders analyze findings and co-create solutions toward the best possible outcomes. While it is an independent process, it brings tremendous value to bear on overall health outcomes and therefore, on program impact.

Additional Resources

Global Fund Materials

COVID-19 Response Mechanism (C19RM) Guidelines

Download in >>

- English
- Español
- Français

C19RM Technical Information Note

Download in >>

- English
- Español
- Français

COVID-19 Response Mechanism (C19RM) - Funding Request Instructions

Download in >>

- English
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Community Updates, Tools, and Guides

C19RM Updates	
1.	[Global Fund COVID-19 Response Mechanism (C19RM)](#) International Council of AIDS Service Organizations (ICASO) in partnership with GATE, AP-CASO/APCRG, and LAC Regional Platform - April 20, 2021
2.	[Meaningful Community Engagement in the COVID-19 Response Mechanism (C19RM)](#) URGENT: The C19RM process at country level is currently underway JOIN NOW! BE INVOLVED! BE HEARD! - International Council of AIDS Service Organizations (ICASO) in partnership with GATE, APCASO/APCRG, and LAC Regional Platform – April 2021
CLM Guides	
3.	[Community-Led Monitoring: A Technical Guide for HIV, TB and Malaria Programming](#) - EANNASO - 2021
4.	[Establishing community-led monitoring of HIV services](#) - UNAIDS - 2021
5	Data for A Difference: Key Findings, Analysis and Advocacy Opportunities from the Regional Community Treatment Observatory in West Africa - ITPC -2019 download in [English](#)	[French](#)
6.	The CTO Model Explained: Summary Brief on Community Treatment Observatories (CTOs) as a Model for Community-led Monitoring – ITPC -2020 download in [English](#)	[French](#) - full publication in [English](#)	[French](#)
7.	[A Toolkit to Sustain Global & National Advocacy: Enabling Women to Track Global Fund Investments Towards Gender Equality Across HIV, Tuberculosis & Malaria](#) - Women 4 Global Fund - 2021
8.	[Ritshidze Community-Led Monitoring Program:](#) website for South Africa's HIV/TB CLM program, contains numerous tools, resources, and program evidence, [including the Activist Guide: Community-led Clinic Monitoring in South Africa](#) - The Ritshidze project – 2020
9.	[Community-Led Monitoring of Health Services: Building Accountability for HIV Service Quality (White Paper)](#) - HealthGAP, O'Neil Institute, TAC, ITPC, ICW, SMUG, HEPS
10.	[Resources for Watchdogging PEPFAR](#) (People's COP Reports and other resources) - PEPFAR Watch
11.	[Community-led Monitoring:](#) Guides, Tools and Resources - PEPFAR Watch

CLM 101

Global Fund definition of community-based monitoring or CBM

"Mechanisms that service users or local communities use to gather, analyze and use information on an ongoing basis to improve access, quality and the impact of services, and to hold service providers and decision makers to account."

Source: https://www.theglobalfund.org/media/9627/core_css_overview_en.pdf

UNAIDS

"HIV community-led monitoring (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 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 data builds evidence on what works well, what is not working and what needs to be improved, with suggestions for targeted action to improve outcomes."

Source: https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf

PEPFAR

"Community-led monitoring (CLM) is a technique initiated and implemented by local community-based organizations and other civil society groups, networks of key populations (KP), people living with HIV (PLHIV), and other affected groups, or other community entities that gather quantitative and qualitative data about HIV services. The CLM focus remains on getting input from recipients of HIV services in a routine and systematic manner that will translate into action and change."

Source: https://www.state.gov/wp-content/uploads/2020/07/PEPFAR_Community-Led-Monitoring_Fact-Sheet_2020.pdf

The 4 Steps to Implementing CLM

CLM implementation has four key components: education, evidence, engagement, and advocacy. The work begins with education - sharing normative guidance and WHO-recommended standards for prevention of, and testing, care and treatment for multiple diseases, such as malaria, TB, COVID-19, and HIV, the scientific information that these are based on, and why these things are essential to the health, quality of life and survival of people impacted. Communities use this information within their local and national contexts to develop their own indicators – such as access to and uptake of HIV prevention and testing services, the number of people who are receiving continuous antiretroviral therapy (ART) and viral load monitoring, and the quality of these services. After their health and rights literacy has been built (i.e. they have gained an understanding of the science behind the diseases, knowledge of their rights, what information to look for, and why it matters to do so), data collectors gather information on the indicators (whether there are drug stock-outs, the turn-around for viral load test results, etc.), which is the evidence. These evidence and insights are then presented to a multi-stakeholder group, including representatives of national PLHIV networks, service users, healthcare providers and policymakers, normative agencies, etc. who work together to analyze the data and identify priority issues – this is engagement. These stakeholders work together to advocate for improvements while continuously engaging with wider actors to ensure the lasting impact of targeted actions and wider sustainability of CLM at country-level.

-ITPC toolkit (forthcoming in 2021)

Global Fund Board Decision Point

Whenever the Board of the Global Fund makes a decision, the specifics are captured in a "Decision Point" document that articulates all of the details as approved by the Board. The Decision Point that approves the second extension of the C19RM mechanism (GF/B44/ER12 – Revision 2) notes that CLM is needed for the following:

Why CLM is needed	Language in the Decision Point	What it means
To inform C19RM allocations	*Allocation and award of funding:* *17. Data inputs used to inform the adjustments will include data on COVID-19 infections and deaths (and the presence of epidemiologically significant variants), testing rates/positivity, demographics, available data on HTM service disruption (including LFA surveys, facility surveys, **data from community-led monitoring (CLM),** and national metrics), impact on HTM infections/deaths (where available), available data on utilization of C19RM funds already awarded, and information on domestic and other external sources of funding (including with respect to access to key COVID-19 commodities).*	As the Global Fund seeks to determine the allocation of C19RM funding, CLM data about the situation on the ground can influence (and possibly increase) the amount of an award

To address community engagement challenges	*Community engagement and community-led interventions:* *46. To help address these challenges, **the Secretariat will provide support through** available resources and flexibilities to support (financially or otherwise) civil society and community engagement and constituency discussions. Support may be funded through CCM funding (including the CCM Evolution strategic initiative), additional C19RM management and operating funds where relating to CCMs, and **a portion of the centrally managed C19RM funds for broader CRG areas,** e.g. community-led monitoring. The Secretariat will continue to engage at country-level to reinforce these principles, including by leveraging existing initiatives (e.g. the CRG strategic initiative) to strengthen and support community engagement*	According to this board paper, only 6% of total C19RM funding in phase 1 was allocated to community, rights, and gender interventions. Knowing how vital these are for a country's response to COVID-19 and HIV, TB and Malaria (HTM), the Global Fund is working to strengthen community engagement in phase 2, including by making resources available for CLM and CSS more broadly.
To ensure synergies with sixth replenishment grants	*5% funding for centrally managed investments (to enable support for cross-cutting areas)* ***Additional strategic priority areas may include:** centralized technical assistance for the development of C19RM requests and implementation of interventions, given the significant additional resources anticipated, need to embed partner support and technical rigor at country level, and need to ensure synergies with 6th replenishment grants; support for engagement of those most impacted by and vulnerable to COVID-19 in the development and implementation of C19RM interventions; **support for coordination on community-led monitoring (including for reporting on human rights violations and GBV);** and support for global and regional platforms coordinating the COVID-19 response where expertise is new and evolving, and where in-country capacity is limited.*	The purpose of centrally managed and time limited investments is to enable support for cross-cutting areas of need that cannot be addressed through funding requests from individual countries, but that are key for the success of C19RM investments. The Global Fund recognizes that CLM is essential to this success and is therefore making CLM support eligible through centrally managed investments.

| To ensure the success of country-level C19RM investments | *Central management of limited investments:*

 57. The Secretariat anticipates that there may be some targeted needs relating to the global response to COVID-19 that cannot be addressed through country-submitted requests, but that are necessary to ensure the success of country-level C19RM investments. **Some examples of such needs include:** *support to accelerate the introduction of new products (including through pre-qualification) and innovations; support for engagement of those most impacted by and vulnerable to COVID-19 in the development and implementation of C19RM interventions;* **support for global coordination on community-led monitoring (including for reporting on human rights violations and GBV and to address quantitative and qualitative data gaps on HTM services);** *support for community engagement; and support for global and regional platforms coordinating the COVID-19 response, where expertise is new and evolving, and where in-country capacity is limited. The Secretariat recommends that up to 2.5% of any C19RM funds be available for these targeted investments, which will be centrally managed by the Secretariat. This funding is separate and distinct from the catalytic funding under existing Strategic Initiatives, although the Secretariat will ensure that there is no duplication or misalignment with existing Strategic Initiatives.* | The Global Fund recognizes that CLM improves program outcomes. Global coordination of CLM will help to share country-level best practices, address challenges, document progress, and quickly identify new findings in the context of COVID-19 to strengthen advocacy outcomes, and ultimately, better HTM programs. |

Recent examples of CLM adaptation for and during COVID-19

During the final months of 2020, ITPC implemented a short-term community-led monitoring project in Sierra Leone to assess the impact of COVID-19 on access to, and quality of, HIV and TB treatments, as well as on human rights. The work focused on high-volume, urban facilities.[1]

The Network of HIV Positives in Sierra Leone (NETHIPS) was able to leverage its existing and strong relationships with networks of people living with HIV and TB to lead an indicator definition process for HIV, TB, human rights, and COVID-19. They ensured that indicators were customized to the context. Data collection took place over a four-month period and quickly translated into calls for action, including the following:

CLM Finding	Advocacy and Impact
• Data collected showed a declining trend in GeneXpert TB testing in Sierra Leone from September to November 2020. This finding validated community concerns that GeneXpert machines were being overwhelmed and monopolized by COVID-19 testing, and that TB had been deprioritized by healthcare workers and laboratories as a result.[2]	• CLM partners are using this data to reinforce advocacy messaging from a recent Stop TB Partnership community report, calling on governments to leverage testing platforms like GeneXpert to increase COVID-19 testing capacity while ensuring that TB testing not be stopped.[3]
• By collecting age-disaggregated data, the CLM model revealed that one-third of the people on ART who were lost-to-follow-up each month were young people.	• Partners are emphasizing the importance of using digital tools such as text messaging and social media platforms to re-engage young people.

Monitoring service access and client satisfaction for key populations in Malawi

Pakachere Institute for Health and Development, an NGO based in Lilongwe, Malawi, supports HIV prevention, care, and treatment interventions for female sex workers (FSW). Pakachere receives USAID support through the local endeavors program. The NGO implements an observatory client satisfaction survey through a CLM model that uses clients seeking services as the principal investigators and respondents at the same time. The peer educators/FSW observe and document issues affecting the quality of services at local healthcare facilities and note the challenges from a lived experience perspective. They share this information in real time to inform evidence-based advocacy for better services for FSWs.

Some notable improvements and changes made as a result of this observatory and lived experience reporting include the following:

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1   This CLM project was part of a larger five-country study that also included China, Guatemala, India (which monitored TB indicators only), and Nepal. Funding support was provided by UNAIDS.

2   *Wits University (2020). GeneXpert testing platform for TB repurposed to accelerate testing for Covid-19. Online at* https://www.wits.ac.za/covid19/covid19-news/latest/genexpert-testing-platform-for-tb-repurposed-to-accelerate-testing-for-covid-19-.html

3   *Stop TB Partnership (2020). The impact of COVID-19 on the TB epidemic: A community perspective. Page 10. Online at* http://www.stoptb.org/assets/documents/resources/publications/acsm/Civil%20Society%20Report%20on%20TB%20and%20COVID.pdf

CLM Finding	Advocacy and Impact
• A drop in the numbers of FSW clients was noticed and recorded in Mangochi health service drop-in center. An investigation conducted through the observatory CLM mechanism established that one of the facility staff members had negative attitudes towards FSW.	• Pakachere used this information to conduct service provider capacity building training and orientation of health facility staff on KP service provision which resolved the issue of stigma and negative attitudes towards FSW.
• Challenges were reported in accessing ART outside the facilities where ART was initially begun. Due to the mobile nature of their profession, FSWs often find themselves far from the healthcare facility when their drugs run out. When they wish to access drugs from another facility, they are required to present a health passport.	• Pakachere used this information to engage with Ministry of Health and this requirement was removed, thus allowing FSWs to get treatment and drug refills from any facility in the country.
• Sexual and gender-based violence (SGBV) survivors did not receive adequate psychosocial support as healthcare facility staff would only provide clinical treatment.	• This challenge was brought up in health management discussion forums. As a result, healthcare facilities now have a focal person to look into issues of SGBV against FSWs. SGBV survivors are now able to access treatment and psychosocial support services in a more structured manner.

"Rights - Evidence - Action (REAct)"

Community-led monitoring has been used to monitor and understand the ways in which violence and human rights violations impede access to HIV services. The "Rights - Evidence - Action (REAct)" has been implemented by Frontline AIDS and national civil society partners since 2014, spanning more than 20 countries.[1]

Community-based monitors known as 'REActors' receive training in basic human rights theory, carry out semi-structured interviews, and document human right violations in a specialized information management tool. Each REAct implementing organization owns the data it collects, and is responsible for monitoring, analyzing, and using this data to inform their own programming.

Between 2014 and 2018, 234 community representatives were trained on REAct and on human rights-based HIV monitoring; nearly 50 CBOs and Frontline AIDS partners provided direct emergency responses to human rights and violence-related needs among community members; and 686 cases of violations were documented, responded to, or referred to other services.

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[1]   22 countries used REACT between 2014 and 2018: Bangladesh, Botswana, Burundi, Egypt, Eswatini, India, Kenya, Lebanon, Lesotho, Malawi, Mozambique, Myanmar, Namibia, Nigeria, Senegal, South Africa, Sudan, Tunisia, Uganda, Yemen, Zambia, Zimbabwe. The following countries were expected to use REACT between 2019 and 2020: Botswana, Burundi, Eswatini, Georgia, India, Jordan, Kyrgyzstan, Lebanon, Lesotho, Malawi, Myanmar, Moldova, Morocco, Mozambique, Namibia, Nigeria, Senegal, South Africa, Tajikistan, Tunisia, Uganda, Ukraine, Zimbabwe. Also in the process: West Africa regional. 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

CLM Finding	Advocacy and Impact
• Cases documented through REAct revealed the extent to which access to HIV services was impeded by human rights violations.	• In 2019, the Tunisian parliament passed the Organic Law on the Elimination of All Forms of Racial Discrimination in Tunisia. Evidence from cases documented under REAct contributed to this decision.
• REAct documentation captured breaches of confidentiality and ethical practices at state-run health facilities.	• In 2018, Lebanon passed a law for the protection of people living with HIV. Evidence generated by REAct was presented in parliament to advocate in favor of passing the law. This same evidence influenced authorities to regulate and sanction harmful practices at state-run health facilities.
• Rights violations documented via REAct helped inform a research report by Sexual Minorities Uganda (SMUG), entitled "And That's How I Survived Being Killed." The report included 264 documented violations.	• In the pre-election campaign window, the report was used to sensitize candidates on the issues.

Impacts of COVID-19 on children living with HIV and their care givers in Uganda

In March 2020, the government of Uganda implemented a wide-reaching national policy response to COVID-19 that included a suspension of public and private transport, border closures, a nighttime curfew, and the closure of many businesses. Concerned about the impact of these sweeping measures on the pediatric HIV response, a group of community organizations - Health GAP, the Coalition for Health Promotion and Social Development (HEPS Uganda), the National Forum of People Living with HIV/AIDS Networks Uganda (NAFOPHANU) and allies – interviewed 88 caregivers of children with HIV from across Uganda to document immediate and longer-term effects of the COVID-19 response on children and their families. While not CLM, this assessment was possible because it used the community infrastructure that CLM in Uganda has established, enabling a thematic 'deep dive' into the preventable community harms brought about by the national COVID-19 response. These adaptations extend the impact of CLM by ensuring communities can respond in real time to emergent barriers.

Publishing their findings in a community report, <u>Left Behind Under Lockdown</u>[1], ,this snap survey in the midst of COVID-19 revealed devastating realities for children living with HIV, including widespread abandonment by PEPFAR, the Global Fund, and Ministry of Health-supported programs. The findings from the report were used to secure policy shifts from donors. However, ongoing watchdogging and routine monitoring will be needed to ensure donor accountability.

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1   Source: <u>https://www.heps.or.ug/publications/left-behind-under-lockdown-impact-covid-19-restrictions-children-hiv-and-their</u>

CLM Finding	Advocacy and Impact
• COVID-19 led to disruptions of regular routines and ways of living, including children being housed with different family members, sometimes in different districts. Health systems failed to meet the moment: slow and unnecessarily complicated inter-facility patient transfers led to HIV treatment disruptions. These had tragic consequences for children living with HIV – as documented in video testimonials collected via CLM.	• Community evidence was used to secure policy shifts from donors, including commitment to making inter-facility transfers by patients easier.
• Lockdown measures seriously hampered access to HIV-related services and care. For months, families were unable to move freely, unable to earn an income, and faced major barriers when they sought essential services such as medical care.	• CLM documentation of these barriers was used to win policy solutions, including roll out of cash transfers, transport vouchers, and other essential interventions to undo the harms caused by the national COVID-19 response.
• CLM documented the specific challenges and barriers that arose for children living with HIV, which enabled advocates to develop a list of urgent policy recommendations for duty-bearers.	Policy solutions identified include: • In consultation with directly affected communities, design, fund and implement an emergency pediatric COVID-19 "catch up plan" to help families recover as quickly as possible; • Initiate direct cash transfers to children living with HIV and their families, as well as other evidence-based social protection measures to enable them to buy sufficient nutritious food and other household goods; • Mobilize community health workers and NGOs in a coordinated effort to identify and assess all children living with HIV, and refer those whose health has deteriorated during lockdown for further testing and support.

Key entry points for engaging on CLM throughout the C19RM process and reflection questions:

National COVID-19 task team	C19RM funding request	Technical review panel	Grant making	Grant implementation
• Does the national task team include members from civil society and communities? • Do regular COVID-19 task team meetings assess (i) disruptions to health services due to the pandemic; ii) what information gaps exist; iii) is community-led data used to inform the national response, (iv) Have you looked at how to monitor human rights violations? • Are civil society and communities of people with HIV, TB, and malaria and their KPs meaningfully engaged in consultative dialogues? • Are community-led interventions recommended by the national task team?	• Are civil society, KP, and communities meaningfully engaged in the consultations and dialogue sessions? • Does the CCM have a dedicated focal person for community engagement? • Is CLM included among the recommended interventions in the funding request? • How are CLM activities costed	• How can civil society, KPs, and communities meaningfully engage when responding to Technical Review Panel (TRP) comments? • Once CCM shares TRP comments with stakeholders, are civil society representatives prepared to respond within the given timeframe? • Is hiring a technical consultant recommended to provide support in responding to questions about community responses and systems (including CLM)?	• How can civil society, KPs, and communities meaningfully engage during grant-making? • Are the proposed CLM implementing organizations community led? • How should CLM mechanisms be adequately budgeted for? What are the indirect costs for CLM that should be adequately budgeted for?	• How can CLM data be integrated into national reporting systems? • How is CLM data used for decision making, including during implementation of GF programs? • How can CLM data be made reliable and dependable with respect to ethics and confidentiality? • How are we ensuring data ownership and security?

Sample Indicators for CLM

The following tables are examples of indicators used in a recent CLM project led by ITPC during the COVID-19 pandemic. This list of indicators is not proscriptive. You can also have a look at other examples, like the Ritshidze assessment tools, available here: https://ritshidze.org.za/category/tools/

Health Facility Quantitative Indicators (HIV)

Indicator	Disaggregates
1. Number of PLHIV newly initiated/enrolled onto ART - SAME DAY	
2. Number of PLHIV newly initiated/enrolled onto ART - NOT SAME DAY	
3. Number of PLHIV who received a baseline CD4 count before initiating ART	male/female, pregnant women and age group (0-17, 18-24, 25+)
4. Number of PLHIV who received a viral load test	
5. Number of PLHIV on ART at the health facility	
6. Number of PLHIV on ART who are virally suppressed	
7. Number of PLHIV who have treatment failure	
8. Number of PLHIV who are lost to follow-up (LTFU)	
9. Number of people initiated/enrolled onto TB treatment	
10. Number of PLHIV who tested positive for COVID-19	
11. Percentage of key populations reached with HIV prevention programs	Gay men and other men who have sex with men, people who inject drugs, sex workers and by age group (0-17, 18-24, 25+)
12. Number of condoms distributed	male, female
13. Number of PLHIV enrolled in multi-month dispensing of ART	1, 2, 3, 6 months, other
14. Number of PLHIV who received their viral load test results within a given turnaround time	2 weeks, 1 month, 3 months, >3 months
15. Name of medicines that are out-of-stock at the health facility	Name of medication, stock-out duration
16. Names of commodities and equipment that are out-of-stock or out of operation	Name of commodity, stock out duration
17. Type of TB tests conducted	Smear microscopy; rapid molecular test (GeneXpert); clinical diagnosis

Healthcare Worker Qualitative Questions (HIV)

Question
1. Tell me a bit about yourself.   What is your role at this healthcare facility?   How long have you been doing this work?
2. How has COVID-19 affected you personally?
3. How has COVID-19 affected your health facility?
4. How has COVID-19 affected healthcare for PLHIV?
5. How has COVID-19 affected your facility's HIV and TB testing and treatment programmes?
6. What are the impacts of COVID-19 on the use of medicines and medical equipment in your facility?
7. What are the impacts of COVID-19 on the use of medicines, commodities, and equipment in other facilities that you have heard about (you can keep this anonymous)?
8. What are some of the successes of your facility during COVID-19?
9. How is COVID-19 going to affect healthcare provision in the future?
10. Going forward, how do you see your role in this project to monitor treatment access during the COVID-19 pandemic?

Recipient of Care Qualitative Questions (HIV)

Question
1. Tell me a bit about yourself.
2. What is COVID-19?
3. How is COVID-19 affecting you?
4. What barriers do PLHIV face in accessing ART now?
5. How many months of ART did you receive during your last visit?   1,2,3 6, months or other
6. How many months of ART are you used to receiving? (Circle one) 1,2,3, 6 months or other
7. If the answers to question 5 and 6 are different, what do you believe/feel explains this change?
8. What challenges do PLHIV face in adhering to ART now?
9. How do healthcare workers or community organizations help retain PLHIV and PLTB treatment and care during COVID-19?
10. What examples of stigma and discrimination do PLHIV face now?
11. What are the burdens/stressors of living with HIV or TB during the COVID-19 pandemic?
12. If you (PLHIV) miss your medical appointment, how do the HCW and others follow-up with you?
13. How are PLHIV and TB getting information about COVID-19? What are they learning?
14. How has the COVID-19 pandemic specifically affected women (and women living with HIV in particular)?
15. How has the COVID-19 pandemic specifically affected men (and men living with HIV in particular)?
16. How has the COVID-19 pandemic affected other people (and other people living with HIV in particular)?
17. How is the government fulfilling its promises stated in the national HIV, TB, and COVID-19 plans?
18. Have you faced changes in fees to get your medicines?
19. Going forward, how do you see your role in this project to monitor treatment access during the COVID-19 pandemic?

Integrating Community-Led Monitoring (CLM) into C19RM Funding Requests

Glossary of terms

ART • Antiretroviral therapy

C19RM • The Global Fund's COVID-19 Response Mechanism

CBM • Community-Based Monitoring

CCG • Community Consultative Group

CLM • Community-Led Monitoring

CLM implementer • Organization implementing a CLM project, generally a civil society organization

CSS • Community Systems Strengthening

EANNASO • EANNASO - Eastern Africa National Networks of AIDS and Health Service Organisations

Host organization • Lead organization of a CLM project, and responsible for functions including budget and program oversight, administrative tasks, grant reporting, and in some cases, sub-granting

HTM • HIV, TB, and malaria

ITPC • International Treatment Preparedness Coalition

KP • Key populations

Project site • Location where CLM data collection takes place (could be a physical space, such as a clinic or health center, or a virtual space, such as an online support group)

HSM • Public health and social measures

PLHIV • People Living with HIV

PPE • Personal Protective Equipment

RSSH • Resilient & Sustainable Systems for Health