COMMUNITY LED MONITORING

A TECHNICAL GUIDE FOR HIV, TUBERCULOSIS AND MALARIA PROGRAMMING

LIST OF ACRONYMS

AGHA	Action Group for Health, Human Rights and HIV/AIDS in Uganda
CLM	Community Led Monitoring
CCM	Country Coordinating Mechanism
CEDEP	Centre for the Development of People
CISMAT	Civil Society Movement Against tuberculosis
CITAM+	Community Initiative for Tuberculosis, HIV/AIDS and Malaria +
COMPASS	Coalition to Build Momentum, Power, Activism, Solidarity and Strategy in Africa
COP	Country Operational Plan
CSO	Civil Society Organizations
CS	Civil Society
EANNASO	Eastern African National Networks of AIDS and Health Service Organizations
FSW	Female Sex Workers
HEPS	Coalition for Health Promotion and Social Development
HIV	Human Immunodeficiency Virus
ITPC	International Treatment Preparedness Coalition
JONEHA	Network of Journalists Living with HIV
KP	Key Populations
MANERELA+	Malawi Network of Religious Leaders Living with or Personally Affected by HIV AIDS
MSM	Men who have Sex with Men
NAFOPHANU	National Forum of people living with HIV in Uganda
OC	Oversight Committee
PAPWC	Pan African Positive Women Coalition, Zimbabwe
PEPFAR	The President's Emergency Plan For AIDS Relief
PLHIV	People Living with HIV
PR	Principal Recipient
SR	Sub Recipient
TB	Tuberculosis
UNAIDS	The Joint United Nations Programme on HIV/AIDS (UNAIDS)
UNASO	Uganda Network of AIDS Service Organizations
UNYPA	Uganda Network of Young People Living with HIV/AIDS
ZATULET	Zambia Tuberculosis and Leprosy Trust
ZYP	Zambia Youth Platform

ACKNOWLEDGEMENTS

FOREWORD

This document guides communities, movements, and partners to "Think big", by designing and scaling strong Community Led Monitoring (CLM) systems that actively support oversight at national level. More than just service recipients, communities are game changers, offer valuable experience, expertise and leadership in governance, implementation, and oversight. They are best placed to monitor service availability, accessibility, acceptability, affordability, quality, and advocate for improvement. Through collective knowledge and leadership, communities develop solutions that are more acceptable to beneficiaries.

In recent years, there has been increased interest in (CLM), due to realization by stakeholders that top down models hardly provide a full picture of local realities. To the Global Fund, CLM is one aspect of the overall community engagement spectrum. It provides a critical avenue identifying and addressing bottlenecks in engaging and retaining people along the prevention and treatment cascades for HIV, Tuberculosis (TB), and malaria. The immense value of community data collection can be seen in the kind of information and observations resulting from CLM, which often differ widely from the results of monitoring processes performed by governments.

Awareness and interest in improving support for CLM has been growing within the Global Fund and among technical partners, including Stop TB Partnership and UNAIDS. This is reflected in a series of global consultations including the Global Fund Technical Evaluation Reference Group (TERG) report in 2019, which concluded that "CLM is underutilized", urging that it should be scaled up while community data systems are strengthened and linked to the national information systems so that access to quality services may be improved.

Still, CLM is not systematically applied in many countries, featuring only as small initiatives or activities. While funding is a major obstacle, designing locally developed CLM initiatives at scale has been a major challenge. This guide consolidates technical advice on all phases of CLM implementation, and offers valuable, practical advice and lessons learned by current practitioners with a view to addressing these challenges.

INTRODUCTION

The Global Fund to fight AIDS, tuberculosis and malaria's strategic plan and partners' disease-specific strategies for HIV, Tuberculosis (TB) and malaria all recognize the pivotal role of Resilient and Sustainable Systems for Health (RSSH), most especially that of Community Systems Strengthening (CSS) including CLM in improving equity, access and quality of health services, in attaining Universal Health Coverage and accelerating the end of the epidemics.

Every three years, the Global Fund issues allocation letters to eligible countries detailing their respective funding allocations and invites Country Coordinating Mechanisms (CCMs) to develop and submit funding requests. The Global Fund through its modular framework handbook[1] has prioritised the CSS module and provided examples of acceptable CLM interventions within the broader RSSH module. The modular framework provides countries with the necessary impetus to prioritize and invest in CLM along with other HIV, Tuberculosis (TB), malaria, and systems strengthening priorities. There is however limited simplified information that may enable communities to better understand CLM and how to integrate it into funding requests.

Who can use this guide?

This technical guide may inform civil society organizations at the grassroots and other levels, communities, CCMs and consultants to design, cost and implement CLM correctly, as one of the main interventions within the Global Fund's CSS module. It may also inform other implementing partners including community groups and networks; civil society organizations, movements, activists, Principal Recipients (PRs), Sub Recipients (SRs) of Global Fund grants and The President's Emergency Plan For AIDS Relief (PEPFAR) implementing partners; government departments, technical assistance providers and organizations; civil society advocates, Country Coordinating Mechanisms (CCMs) and other oversight and decision-making bodies.

Development of this guide was informed by extensive experience on existing CLM mechanisms implemented by local organizations in Malawi, Sierra Leone, Tanzania, Uganda, and Zambia with support from a range of funding partners including, USAID and the Global Fund. In addition, the authors referred to the following resources.

- Community-based monitoring: An Overview, The Global Fund, May 2020
- The Stop TB Partnership: Community-based monitoring of the TB response, using the OneImpact digital platform OneImpact Investment Package)
- Expertise France: Report on Community Health Observatories
- PEPFAR: Community-Led Monitoring Tools Community Led Tools https://www.pepfarsolutions.org/tools-2/2020/3/12/community-led-monitoring-implementation-tools
- FRONTLINE AIDS: REACT User Guide for documentation and monitoring of human rights https://frontlineaids.org/resources/react-user-guide/
- ITPC's Regional Community Treatment Observatory in West Africa and the Missing the Target
- French 5% Initiative: https://www.initiative5pour100.fr/sites/default/files/ressource-doc/2019-10/Community-health-observatories-capitalization_0.pdf
- ITPC, Community-Led Monitoring and Advocacy for Health (PDF)

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1   Modular Framework Handbook, The Global Fund, October 2019

PART I

PART I UNDERSTANDING COMMUNITY LED MONITORING

1.1 What is Community Led Monitoring (CLM)?

Community Led Monitoring (CLM) is also often referred to as Community Based Monitoring (CBM) and is defined by the Global Fund as, "Mechanisms that service users or local communities use to gather, analyse and use information on an ongoing basis to improve access to, quality and the impact of services, and to hold service providers and decision makers to account"[2].

CLM mechanisms avail service users and communities a platform to gather qualitative and quantitative data and use it to assess availability, accessibility, acceptability, equity, and quality of the services they receive, using that information to hold service providers and decision makers accountable. The value of CLM is summarized this short video from the Global Fund's website. https://www.theglobalfund.org/en/video/2020-04-15-community-based-monitoring/

Other partners including With the Joint United Nations Programme on HIV/AIDS (UNAIDS), Stop TB Partnership, Roll Back Malaria, the German Federal Ministry for Economic Cooperation and Development and the Swiss Development Cooperation, PEPFAR, the French 5% Initiative, international civil society and some private sector entities also recognize CLM mechanisms as one of interventions under CSS that facilitate safe, need based, accessible and high-quality services and structures necessary to end the epidemics and develop resilient and sustainable systems for health (RSSH).

CLM recognizes communities have unique attributes that can be nurtured and tapped to improve planning and health service delivery at community level. Among these are the capacity to advocate effectively, play the 'Watch dog" role, utilize experiences to advise on what works and what does not. Communities are effective implementers of testing and screening, adherence support, stigma reduction, social accountability, and many other services[3].

Ultimately, CLM holds both government and non-state service providers accountable for responding to intended beneficiaries' needs; strengthens community engagement and ownership; fills public health system information gaps; responds to human rights and gender-related barriers; monitors budgets; and prevents stockout and expiry of commodities. This is mostly achieved by routinely collecting data to establish gaps in service delivery; and to respond to the identified limitations in the quality of services such as availability of health workers, commodity stocks outs, gender, and human rights barriers to services. CLM is also about

holding services providers including government (Ministry of Health), and non-governmental implementing partners at health facility and community level accountable for services they deliver. In doing so, CLM creates ' community level quality assurance advocates' who identify and document gaps and constraints in equity, access and quality of prevention, treatment services and challenges adversely affecting service delivery; and use the information to influence and advocate for positive changes and improvements at all levels namely the facility, county, district, regional, provincial and national level policy reform; and can also be used to inform decision and program design by national disease programs for HIV, TB and malaria.

Who benefits from CLM? In the context of HIV, TB and malaria, beneficiaries at community level may include people living and affected by the diseases, key and vulnerable populations specific to HIV and TB who either account for high incidence and prevalence rates, or for the majority of missing cases. HIV related key[4] and vulnerable populations include female sex workers, people living with disabilities, men who have sex with men, transgender, people who inject drugs and their movements or networks, uniformed forces, women, adolescent girls, and young women and youth. These may vary according to country contexts. Key affected populations under TB include miners, health care workers, prisoners, urban slum dwellers and the rural poor[5]. Populations at high risk of contracting malaria include expectant mothers, infants, children under 5 years of age, patients living with HIV, migrants, and mobile populations[6].

Why the various forms and labels of CLM? CLM mechanisms often differ depending on the country, their objectives and implementing partner. For example, a Malawi project supported by USAID and implemented by Pakachere Institute for Health and Development (PAKACHERE)implements a CLM mechanism focused on monitoring quality of services amongst sex workers in target districts is referred to as a Client Satisfaction Survey. In Zambia and Malawi, Community Initiative for Tuberculosis, HIV AIDS and Malaria+ plus and Malawi Network of Religious Leaders Living with or Personally Affected by HIV AIDS (MANERELA) implemented CLM pilots monitoring quality and access to services by PLHIV in target facilities in one location with support from the International Treatment Preparedness Coalition (ITPC). These CLM mechanisms are referred to as 'Community Treatment Observatories" while Civil Society Movement Against Tuberculosis (CISMAT) in Sierra Leone monitors quality and access to services by people affected by TB.

CLM is NOT monitoring and evaluation: CLM should not be equated to routine monitoring and evaluation undertake by implementing partners including PRs and SRs who engage communities to attain their perceptions and feedback on services rendered to them. Any other initiative that utilizes data collectors not drawn from the community of service users including People

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2   Community-based monitoring: An Overview, The Global Fund, May 2020
3   Stop TB Partnership, Meaningful Participation of TB Communities in National Planning
4   https://www.theglobalfund.org/en/key-populations/
5   http://www.stoptb.org/assets/documents/communities/FINAL%20Declaration%20on%20the%20Right%20of%20People%20Affected%20by%20TB%2013.05.2019.pdf
6   https://www.who.int/malaria/areas/high_risk_groups/en/

Living with HIV (PLHIV), Key Populations (KPs), people affected by TB, communities affected by malaria does not constitute CLM. The overall objective of CLM empower and capacitate communities as right holders and change agents to facilitate equity, access, and quality in the delivery of health services at community level. This is achieved through capacity building, and the subsequent monitoring and documentation of the first-hand experience of service users on the barriers to access and quality of services; and using the information for advocacy to influence improvements in service delivery.

The Global Fund, With the Joint United Nations Programme on HIV/AIDS (UNAIDS), the Stop TB Partnership, Roll Back Malaria, the French 5% initiative, PEPFAR and The German Federal Ministry for Economic Cooperation and Development and the Swiss Development Cooperation are some of the funding and technical partners that have prioritised support of the design and implementation of CLM mechanisms.

1.2. PRINCIPLES OF COMMUNITY LED MONITORING (CLM)

i. CLM is about community empowerment

Community empowerment is a process of re-negotiating power in order to bring about social and political changes and to gain more control. It addresses social, cultural, political, and economic determinants of health, and builds partnerships with other sectors to find solutions[7]. CLM involves sensitizing and building capacity within communities to know their respective epidemics (know your epidemic) rights, ("Know your rights") and understand programs and grants; CLM is about equipping them with planning, monitoring, organizing, assertiveness, and advocacy skills in order to be effective change agents and duty bearers in their respective communities. Such knowledge includes bio-medical, behavioral, and structural barriers to health service delivery; and indicators relevant to their respective CLM mechanism.

> "
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ii. Community Led Monitoring is community led and driven

UNAIDS defines community led organizations as those which, "are led by the communities and/or people they serve and are primarily accountable to them"[8]. Communities in this sense may be equated to the ultimate program beneficiaries. In many contexts, including in challenging operating environments, grassroots non-governmental and community-based organizations are an integral part of community led organizations. Community led organizations include key population (KP) led organizations.

"Community led and driven" means that either PLHIVs, people affected by TB and communities affected by Malaria must be an integral part of the decision to establish CLM mechanisms and should meaningfully participate at all levels – including in setting objectives, defining what CLM will monitor, selecting data collectors, and recording information. Lastly their holistic involvement should entail meaningful participation in analysis and interpretation or making sense of collected information, and using it for advocacy, decision making, priority setting, policy change and program improvement.

iii. CLM is objective and transparent

CLM mechanisms uphold the principal of impartiality and neutrality. Community led organizations which are active implementers of interventions and service providers do not qualify as potential CLM implementers. This is because such organizations will be 'subjective' and have 'conflict of interest'. This could undermine overall effectiveness and credibility of the CLM mechanism. Advocacy may not make sense because the conflicted implementer cannot advocate to themselves to change things they are already perceived to be in control of. CLM also fosters a culture of information exchange reflecting the needs of affected communities for optimum healthcare decision making.

iv. CLM is collaborative with active stakeholder engagement

CLM is a community led, objective and collaborative mechanism undertaken by communities either independently or in collaboration with service providers and other possible partners such as researchers, academics and think tanks. Service providers may either be grassroot health facilities, clinics or civil society organizations undertaking community level service delivery.

Where a CLM mechanism is implemented as a collaborative initiative between the community led organization, health facilities and other service providers, the relationship should be cordial, mutually beneficial, and free of mistrust. Trust is built when all stakeholders are clearly oriented on CLM processes during its planning stages, to build consensus. Relevant stakeholders consist of health facilities, all sub national (district/county/province/ state level) health medical officers, health management teams, police and other law enforcement agencies, elected members of parliament, legislative officers, linked offices at national level and members of Country Coordinating Mechanisms (CCMs), including their oversight committees. Stakeholder engagement should be initiated at the beginning or launch of the CLM mechanism,

7   https://www.who.int/healthpromotion/conferences/7gchp/track1/en/
8   https://www.unaids.org/sites/default/files/media_asset/what-is-a-community-led-organization_en.pd

throughout the course of implementation and at forums disseminating or advocating around CLM findings.

v. Community Led Monitoring is action-oriented and transformational

The goal of CLM is to stimulate positive and corrective action that improves access, uptake, and the quality of health services. Feedback should always strive to be constructive. CLM assesses current health practices to identify, document and communicate identified gaps within a reasonably short time. It transforms findings into advocacy action at various levels. Such information may also show whether a program is achieving intended results.

Feedback loops for CLM mechanisms i.e. from identification of barriers and limitations to advocacy should last between three to six months, or shorter. The feedback loop for large scale CLM mechanisms collecting a lot of information may last longer but should always strive to be as short as possible.

vi. CLM promotes accountability for health investments and results

Through continuous monitoring, CLM mechanisms promote accountability for investments at community level. Through corrective action and improvements, they promote value for money and results which are critical in the strengthening RSSH and in facilitating impact

vii. CLM provides a complementary source of information

CLM mechanisms provide and generate alternative and complementary information through a structured process that entails routine data collection and monitoring of the availability of tools, equipment, materials, supplies and stock of medicines, and health workers with the required competencies and skills mix to match community health needs; the accessibility of health facilities and services including the gender and human rights barriers to HIV, TB and malaria services ; the acceptability of health services i.e. are patients treated with sufficient dignity and trust to promote the uptake of services and appropriateness of health services.

CLM amplifies the voice of communities and service beneficiaries through a structured and constructive process, with short feedback loops that leads to improvements in the access, uptake, and the quality of health services.

> " The goal of CLM is to stimulate positive and corrective action that improves access, uptake, and the quality of health services.

PART II

PART II INTEGRATING CLM INTO FUNDING REQUESTS TO THE GLOBAL FUND

2.1 Integrating CLM Into Funding Requests: An Overview

In the delivery of its mandate, the Global Fund is guided by the funding cycle which details key processes and their respective timelines. Funding for Community Led Monitoring can be approved if it is requested under the Resilient and Sustainable Systems for Health (RSSH) Module as a priority to strengthen Community Systems. It is therefore important for communities to understand the Global Fund Funding Cycle and optimize all opportunities for integrating CLM.

2.2 The Funding Cycle

Global Fund processes are easily predictable because they are guided by a sequential funding cycle. It is important to take note of entry points for integrating CLM. These include national program reviews, strategic planning processes, CCM oversight processes and various interactions with the Global Fund such as funding requests, grant-making, TRP iterations, interactions with the Grant Approvals Committee and if approved as a reprogramming measure during grant implementation, among others.

FUNDING CYCLE

NATIONAL STRATEGIES

FUNDING REQUEST

REVIEW

GRANT-MAKING

APPROVAL

APPLICATION PROCESS

EVALUATION AND REVIEW

TECHNICAL COOPERATION AND REPROGRAMMING AS NEEDED

GRANT IMPLEMENTATION

COUNTRY DIALOGUE
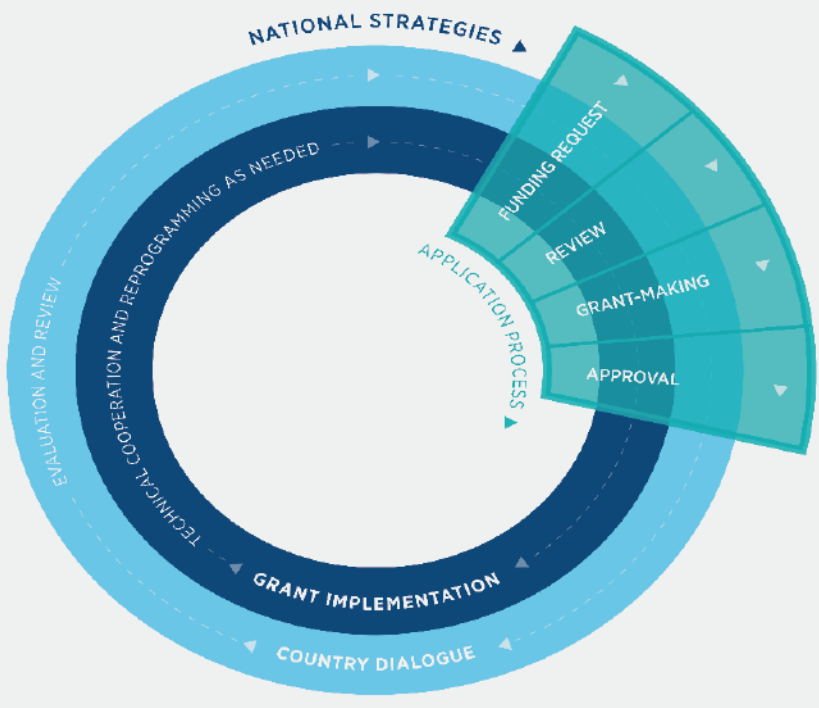
APPLICATION PROCESS : 6-9 MONTHS

GRANT IMPLEMENTATION : 3 YEARS

The Global Fund

a. National Program Reviews

Relevance: National strategic plans (NSPs) for HIV AIDS, Tuberculosis and Malaria provide two primary entry points for integrating the CLM mechanisms into Funding Requests to the Global Fund, namely the NSP program reviews and the subsequent NSP development processes. NSPs are routinely evaluated at their mid-point through mid-term reviews (MTRs). The MTRs provide countries with an opportunity to reflect and take stock of progress made against plans and inform the remainder of the implementation period. For example, if the Strategic covered 2018 to 2020, an MTR review is undertaken after 18 months i.e. after June 2019, to inform the implementation until 2020. At the end of an implementation period, e.g. 2020, a National Program Review is undertaken.

Opportunity

Both the mid-term and program reviews provide important entry points for CLM. They establish the extent to which results were achieved – for example if key and priority populations were retained into care, and if there were service delivery and access gaps. Where gaps and barriers exist, establishment or strengthening of CLM mechanisms should be recommended, since they facilitate continuous identification of such gaps and barriers and provide evidence to advocate for corrective change and improvement.

When undertaking program reviews, National AIDS Control Councils (NACCs), the HIV, TB, and Malaria Programs, CCMs and civil society should ensure that information generated from CLM mechanisms is reviewed as critical data sources that can inform the review process.

It is particularly important for civil society and communities to participate in country dialogue, mid-term and NSP program reviews to provide feedback and articulate the importance of community systems as an integral component of the health system at country level. It is also important for communities to dialogue within their own constituencies/ and contribute to strengthening community systems as a part of building resilient and sustainable systems for health (RSSH). Civil society and communities should ensure that their respective disease-specific national strategies include explicit recommendations on community systems strengthening, including the need for Community Led Monitoring mechanisms as one of its interventions.

b. Development of National Strategic Plans (NSPs)

Relevance: Civil society and communities' participation in the consultative dialogue sessions that began during the disease program reviews should continue during development and validation of the subsequent strategic plans. Routinely, Civil Society (CS) and Communities develop their respective priorities for inclusion into the new NSPs and by extension to their respective funding requests. In developing these priorities, CS and communities should ensure that stakeholders consider feedback and findings generated by various CLM mechanisms to inform the prioritization process.

Opportunity

Similarly, civil society and communities should ensure that their respective disease specific national strategic plans:
- Identify community systems strengthening as an integral component of resilient and sustainable systems for health.
- Interventions are proposed for community systems strengthening; among which should be the establishment of CLM mechanisms.

Clear articulation of CLM as part of CSS in strategic plans is critical since funding request priorities are drawn from NSPs and non-prioritized interventions may not be considered for funding.

c. Funding Request Development

Relevance: Every three years, the Global Fund announces a new funding cycle. The cycle begins when the Global Fund communicates allocation ceilings to country coordinating mechanisms (CCMs) and advises on areas to focus/ emphasize on funding requests. Various technical guides are available from the Global Fund, United Nations, and others to guide communities during funding request processes. The OneImpact Digital Platform developed by the Stop TB partnership is a particularly useful resource for CLM among TB funders. The below diagram summarizes steps in the funding request process.

FUNDING REQUESTS TO GRANT SIGNING
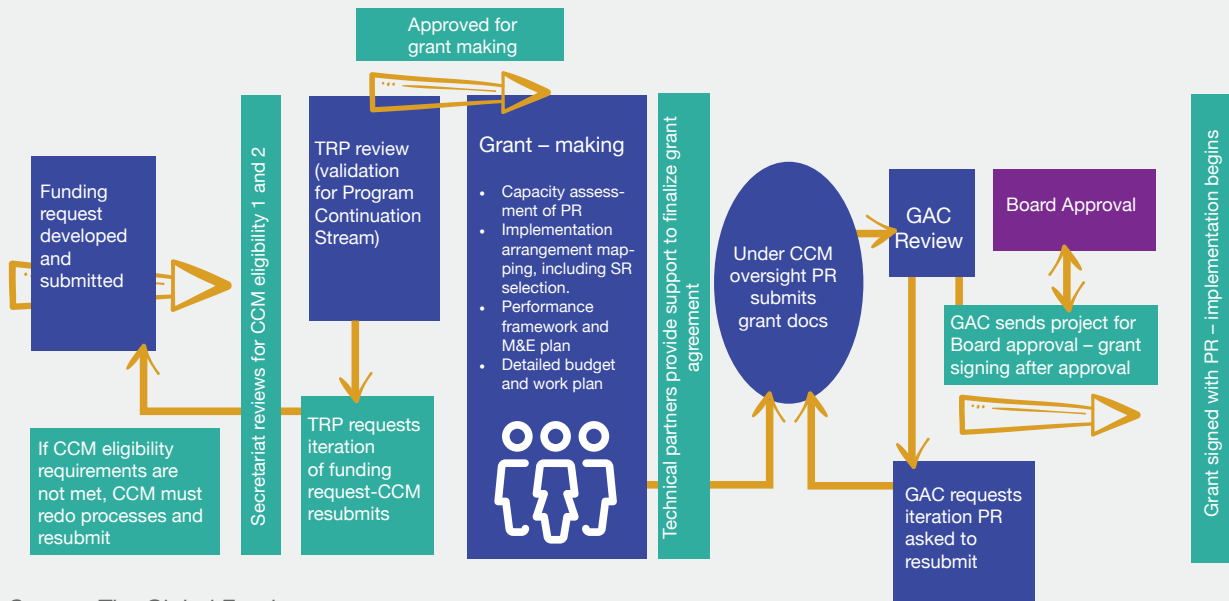
Source: The Global Fund

Opportunity

Consultative dialogue should continue through the NSP and funding request processes and remain informed by data from communities through CLMs where these exist.

Civil society and communities should familiarize themselves with the Global Fund's modular framework, particularly guidance on pages 19 and 20 on CSS available on the Global Fund's website. Under the current modular framework, the modules on RSSH CSS, and reducing gender and human rights barriers to HIV/ TB services provide for CLM interventions and activities. CS and communities should use this guidance to clearly articulate CSS interventions including CLM and ensure that they participate in the work planning and budgeting process to ensure CLM is adequately refined and resourced.

d. Technical Review Panel (TRP) Iteration Requests

Relevance: Once funding requests are submitted by the CCM, the Global Fund secretariat reviews them for completeness and forwards them to an independent Technical Review Panel, for review. If not technically sound, the request is communicated back to the CCM for rewriting. If approved, some technical requests for clarification may be made.

Opportunity

Civil society and communities, especially those on the CCM should follow up on the TRP comments to ensure that where CLM related comments and questions are raised, comprehensive and adequate feedback is provided, and that the Funding Request is strengthened.

e. Grant Making Stage

Relevance: After the endorsement of Funding Requests by the TRP, the FRs proceed to the grant making phase. This phase is mainly undertaken by the selected Principal Recipients (PRs) with the support and oversight of the CCM, Global Fund County Team and technical partners in the country such as UNAIDS, World health Organization (WHO), Roll Back Malaria, Stop TB Partnership, amongst others. Grant making is an important phase under which the capacity assessment of PRs and implementation arrangements, including SR selection are undertaken. It is also during this phase that the performance framework, M & E, detailed budgets and workplans are developed.

Opportunity

Civil society and communities including those on the CCM need to ensure that:
- Implementation arrangements developed include community led organizations as implementers i.e. either sub recipients (SRs) or sub-sub recipients (SSRs) of CLM mechanisms.
- Detailed workplans and budgets adequately fund all components of the defined CLM mechanism.

Civil society and communities' representatives on the CCM must advocate for adequate funding to CLM mechanisms and safeguard the safe from programming during grant implementation.

f. Grants Approval Committee (GAC) Iteration Requests

Relevance: Successful completion of the grant making phase results in the development of grant agreements and documents which are then presented to the Grant Approval Committee (GAC). On review, GAC provides comments, questions, and areas for either clarifications and/or improvements, and these are communicated back to the CCM for action and resubmission.

Opportunity

Civil society and communities, especially those on the CCM should follow up on the GAC comments to ensure that where CLM related comments and questions are raised, comprehensive and adequate feedback is provided to enable Funding Requests proceed to the Board for review and approval.

TABLE 1: ENTRY POINTS FOR INTEGRATING CLM INTO FUNDING REQUESTS TO THE GLOBAL FUND

PROGRAM REVIEWS	NSP DEVELOPMENT	FUNDING REQUEST DEVELOPMENT	TECHNICAL REVIEW PANEL (TRP)	GRANT MAKING	GRANTS APPROVALS COMMITEE (GAC)
• Does the scope of program review include community systems ? • Does the review inlude an assessment of (i) accesss to services (ii) quality of services (iii) Gender and Human rights barriers to services • Are civil society and coommunities of PLHIV, TB, Malaria and their Key Populations meangingfullly engaged in consultative dialogues? • Does the review provide for civil society speciifc and or communities specific consultations? • Does the review recommend commuunity based interventions of how to address issues of access, quality and barriers affecting services?	• Are CSOs and communities meaningfully engaged in the consultations and dialogue sessions for the NSP? • Is there a Technical Working Group (TWG) for community responses and systems strengthening? • Is there dedicated expertise to support the development of (i) commuity responses and (ii) interventions for communty sytems strenghting inclduing CLM? • Are there explicit community resposnes and community systems strengthening interventions recommended within the NSP?	• Are CSOs and communities meaningfully engaged in the consultations and dialogue sessions? Are they represented within the TWGs? • Does the CCM have dedicated TA for the community engagement, and community systems strengthening? • Are there explicit community resposnes and community systems strengthening interventions recommended within the Funding Request? • Is CLM among the reocmemdnaed internvetions under CSS? • Is your CLM model comprehensively deisgned and costed? • have you reocmmended possible locations where the CLM mechanisms can be rolled out, and the implmenting partners?	• Do any of the TRP comments received relate to CLM? • Do you have adequate expertise within the country to respond to CLM questions? • Lead and CSS consultants should be available to help the CCM in respond to CLM related questions	• Which representatives of CS and coomunities including CCM members are participaing in the grant making phase? • Do those participatinging have adequante understanding of CLM • Which orgnanizations have been proposed as implementers of CLM mechanisms? • Are the proposed implementing organisations (SRs and SSRs) community led organisations? • Where there are no community led organisations, which ones are best placed to implement CLM interventions? • Are workplans for CLM well defined? • Are CLM mechanisms well budgeted for?	• Do the any of the comments received from the GAC relate to CLM? • Do you have adequate expertise within the country to response to CLM questions? • Lead and CSS consultants should be available to help the CCM respond to CLM related questions

PART III

PART III DESIGNING COMMUNITY LED MONITORING (CLM) MECHANISMS

The design and funding of robust CLM mechanisms is a key determinant of their success. CLM is process oriented, hence has several interlinked stages. This section guides on how to design and cost CLM mechanisms.

Designing A CLM Mechanism: An Overview

CLMs are best designed by implementing civil society and community led organizations. Empowering these organizations and beneficiaries on their respective patient rights, and equipping them with planning, monitoring, organizing, assertiveness, and advocacy skills is important. This creates effective change agents and duty bearers that can actively improve service delivery.

A CLM mechanism comprises of seven main inter linked phases, namely:

i.   Community and government orientation, community empowerment, and capacity building phase
ii. Planning and conceptualization phase- involving community mobilization and entry,
iii. Development and pretest of software and tools,
iv. Data collection, triangulation, analysis, and reporting phase,
v.   Influencing and advocacy phase,
vi. Follow up stage - when recommended actions by decision-makers, oversight bodies and policymakers are followed up with intended implementers,
vii. Monitoring and review phase - where implementation of emerging actions and the effectiveness of the CLM mechanism is continually analyzed and improved.

The phases are both logical and progressive, with each step laying a foundation for the next.

This conceptual framework describes the process of setting up and implementing the CLM mechanism. The process allows all CLM implementers to think through and develop detailed workplans and budgets for each phase, based on their local realities. The diagram summarizes the main phases in setting up and running a CLM mechanism.

CONCEPTUAL FRAMEWORK FOR A CLM MECHANISM

3.1 Community Empowerment Phase

The community empowerment phase is a foundation stage when developing a CLM mechanism since it ensures that communities are 'CLM-ready" and in a position to meaningfully participate in all subsequent phases. During this phase, communities as right holders and government as duty bearers are oriented on CLM which is a mechanism through which communities can claim their rights and through which governments are held accountable. In addition, communities and networks are oriented and empowered on their respective rights, on prevention and treatment for HIV, TB and malaria and the expected health service to be delivered to them. Commuinites are also equipped with organization and advocacy skills. An example of Know Your Rights guidance is the TB people and Stop TB Partnership Declaration of the Rights of People Affected by TB.

3.2 Planning and Conceptualization Phase

During this stage, the entire CLM mechanism should be well thought out and summarized into a project concept note ready for implementation. Key questions to answer during this phase include:

a. What are the primary objectives for your CLM mechanism? i.e. Which barriers do we want to monitor and why? Which population (s) and interventions will we focus on? Will our CLM mechanism monitor issues in one disease or will it adopt an integrated approach? For example, will it model monitor the quality of HIV services by PLHIVs; or will it monitor quality of HIV, TB, and malaria services amongst PLHIVs? Several tools can help planners during this phase. A good example is the Stop TB Partnership's CRG investment package used to strengthen human rights, access and quality of services for people affected by TB, which may be found here: http://www.stoptb.org/communities/default.asp#CRGIP.
At this stage, it is also important to determine if there are other organizations implementing similar CLM mechanisms. If some exist, it is important for the community to know and detail their area of specialization and what makes your CLM mechanism unique; and how the CLM's will collaborate to feed back to each other and avoid duplication.

b. Will ethical clearance and approvals be required from government to ensure that the CLM mechanism is conducted in a responsible, ethical and an accountable manner? If yes, it is important that these are processes initiated early and in good time at the onset of the project.

c. How will the CLM mechanism ensure data privacy, and confidentiality to ensure the rights and protections of key, marginalized and vulnerable populations?

d. What experience does the organization have with respect to CLM? How will it be implemented? Will it be more practical to pilot for a few months or a year before going to scale (growing it to cover entire programs or other national locations?) What strategy will the community use to implement the actual CLM mechanism? The strategy should define the following.

    i. *The nature and type of civil society and community-led organizations that qualify and are positioned to implement the CLM mechanism.*

    ii. *The human resource needs of the implementing civil society and or community-led organizations. These main implementers include a CLM Coordinator, M & E Reporting and Learning Officer, Program Support Assistants and data collectors drawn from communities and service users.*

    iii. *Themes covered by the CLM mechanism -. These will be informed the objectives for the CLM. For example, in Malawi, the PAKACHERE CLM mechanism is focused on monitoring access and quality of HIV services for sex workers, whereas CISMAT in Sierra Leone monitors access and quality of TB services amongst TB patients and survivors. Consider adapting a CLM mechanism model that integrates the monitoring of HIV, TB services, and can integrate others in future.*

    iv. *The geographical scope should be informed by the needs, availability for funding and the objectives of your CLM mechanism. CLM mechanisms can focus on community*

level public health centers / facilities and other service providers in the locality or in districts / counties and provinces / states. It is important however that an evidence-based decision with justification is made on why a CLM mechanism is recommended for each specific location. Note that CLM should be undertaken in strategically identified locations based on researched evidence of challenges with respect to access and quality. If multiple facilities experience related challenges, a step by step approach can be used to implement CLM mechanisms from one to the other between 12-24 months. Once the identified challenges are resolved, the mechanism may be phased out in that location and a new one initiated in other locations, or if relevant nationally, can be scaled up.

v.   *How will your stakeholder mobilization and engagement be undertaken? During this phase, communities should be clear on how key stakeholders will be identified and mobilized, influenced, or advocated with to support the CLM mechanism.*

vi.   *Who will perform data collection? Data collectors must ideally be drawn from beneficiaries / service users who access these at community level. What will the eligibility criteria for data collectors be? What renumeration and incentives will they receive? What are the direct costs related to data collection? For example, transport and or communication / internet allowance? All these questions should be answered during the planning and conceptualisation phase. Which digital and mobile solutions will be used? Have the relevant Ministries of Health and Information been engaged, and approvals sought? It is important that these are acquired at the onset during conceptualization. In most countries there are laws and regulations on data privacy that prevent health records from being used. It is important that all necessary approvals are obtained at the onset.*

vii.   *What will be the mode and frequency of data collection – paper or digital? web-based or mobile? Will the data be collected on a weekly or monthly basis? The strategy should also detail whether the electronic and or mobile platforms are readily available for adaptation; or if they will need to be designed and customized to the context.*

viii.   *Who will analyze and synthesize data collectors' findings to generate the report?*

ix.   *What software will be used for data analysis? What capacities will be required to support data analysis?*

x.   *Who will be the target audience for the findings of the CLM mechanism? Who will use these reports? and for what purposes? What type of reports will be generated?*

xi.   *Who will follow up on each of the identified issues to ensure that corrective action is taken to improve access and quality of services?*

xii.   *For how long will the CLM mechanism project be implemented? Will it be a one, two- or three-year project?*

xiii.   *How will the project be sustained following this period?*

xiv.   *How much is it likely to cost? How can savings be made?*

Each of these key questions is further elaborated below. It is recommended that civil society and communities do not rush into implementing CLM mechanisms; but first plan and invest first in their own empowerment and design of these mechanisms before initiating the implementation phase.

"

Each of these key questions is further elaborated below. It is recommended that civil society and communities do not rush into implementing CLM mechanisms; but first plan and invest first in their own empowerment and design of these mechanisms before initiating the implementation phase.

3.3 Stakeholder Analysis and Engagements.

Once a well thought out and comprehensive concept note has been developed, it will be critical to mobilize and introduce the mechanism to all stakeholders. To be more inclusive, a rapid mapping of key stakeholders and service providers is done. This will help identify the focal persons at all levels including the Ministry of Health at facility, divisional, district/ county, regional/state levels and on the CCM. It will also be useful in identifying early and advocating with people who may otherwise act as detractors to the CLM mechanism. It is also important to determine the roles of each group of stakeholders. For example, at community level beneficiaries will have explicit roles related to participating in program design, data collection, and reporting. District, provincial/ state and national level focal persons including the representatives on the CCM (especially the oversight committee) will be critical when undertaking influencing and advocacy, initiation of corrective action and during follow ups.

It is recommended that the CLM mechanism forms a steering committee with clear terms of reference which will include reviewing and providing inputs, participating in advocacy and dissemination of CLM meetings and developing corrective actions. Membership of the CLM steering committee should be balanced, strategic and strive to include high-level health and political leadership who support advocacy. A formal launch of the CLM mechanism is recommended to generate awareness at community level.

3.4 Capacity Building, Development & Pretest of Software & Tools

As part of capacity building, communities should be mobilized and empowered on the package and quality of services to expect from health facilities and other service providers. This knowledge and literacy are important since it helps draw lessons on what works and what does not, while facilitating corrective action. In addition to sensitizing community members, data collectors and other staff should be trained on CLM objectives, tools and required monitoring and reporting skills.

Training will allow data collectors to immediately flag out key issues and gaps such as commodity stock-outs, closure of facilities, availability of key diagnostic infrastructure and any other relevant areas, depending on the main scope or objectives selected for the CLM.

It is important that training content and/ or data collector's curriculum is developed to inform this process. This training should include practical simulation exercises on the use of electronic technologies and tools that will be adopted. Questions on the length of training and the locations i.e. whether at community, district, or national levels, should be answered at this stage. If using digital solutions, the Stop TB Partnership OneImpact on https://stoptbpartnershiponeimpact.org/ or Frontline AIDS REAct on REAct user guide

" Training will allow data collectors to immediately flag out key issues and gaps such as commodity stock-outs, closure of facilities, availability of key diagnostic infrastructure and any other relevant areas, depending on the main scope or objectives selected for the CLM.

3.5 Data Collection, Analysis and Reporting

Once recruitment and training of data collectors is finalized, they should be mobilized to begin collecting data. The startup phase of 1 – 6 months usually requires intense support on how to collect, document / record and relay information, especially if electronic and mobile communication will be used. Outstanding issues will be flagged out at this stage. Data will be analyzed using procedures defined in the project concept note. Data analysis software may be required, and staff trained on their use. Once findings are generated and analyzed, validation meetings should be planned (and budgeted earlier) to relay information to community members and other stakeholders, summarize an advocacy agenda and discuss how to use findings for advocacy and triangulation (offer CLM as an additional source) of information available to decisionmakers. Such community-led meetings facilitate community ownership and grow members into key drivers of change.

During the design and planning stage, each CLM mechanism should define the nature and type of report to be produced, and their frequency of reporting. Reports generated consistently and at regular intervals throughout the lifespan of the CLM mechanism have proven to be more effective than one--off assessments and scorecards. These reports should be brief, use clear and simple language and be shared in formats that can easily be understood. They should point out key gaps (missing services or commodities), constraints (gaps and barriers arising from issues other than lack of resources) and other identified challenges. The reports should include dates and geographical locations from where findings were generated.

Good CLM reports should specify and summarize community and facility level findings so that stakeholders can select the right people to verify and follow up on recommended actions. Where many locations are implementing the CLM, a consolidated version of the report should be produced.

3.6 Influencing and Advocacy

Influencing and advocacy should be undertaken using an elaborate approach which should entail:
- Sifting and listing urgent and priority observations and bringing them to the attention of the health facility or implementer, the district level steering committee of the district health management team and the CCM where applicable. Relevant feedback should be relayed back to the target community so they may implement necessary behavioral change and other corrective measures.
- A brief advocacy agenda, preferably in bullet points that identifies priority issues, key messages, audiences and communication channels (health sector review meetings, official gatherings, special sittings, campaigns etc.) tools (social and mass media, SMS campaigns, letters, etc.) and timelines should be developed and agreed at this stage, to ensure community members pass the same messages so that the collective energy of communities is targeted towards the right changemakers.
- Applying or using the consolidated periodic CLM reports generated.

Existing CLM mechanisms have used score cards, formatted reports, while some including ITPC have developed shadow reports. http://itpcglobal.org/wp-content/uploads/2015/02/MTT11_Research-Report-FINAL.pdf. It is important that CLMs rely on credible and verified information. Emerging reports should be disseminated widely to intended users and changemakers within the communities and networks, civil society spaces or public health sector, including facilities, MOH, CCM, development partner meetings, and if necessary, parliamentary portfolio committees, or higher levels of government.
- CLM reports should also be disseminated and considered as integral sources of information when conducting oversight visits, routine supervisions, reviewing implementer performance, assessing principal, or sub recipients, undertaking mid and end term reviews and during development of NSPs, guidelines and funding requests.
- The dissemination and advocacy forums for the reports should provide space for the audience to respond to the key issues and define when corrective action will be taken.

3.7 Follow Up, Monitoring and Closure
3.7   Follow Up, and Reviews

Implementing organizations should take note of commitments, timelines and follow up to ensure that:
- Corrective action is initiated immediately; and if not, some formal and verbal communication (letter, email, or traceable oral communication) or meeting is quickly convened to inform relevant authorities on gaps that threaten health service delivery
- Corrective action is completed within agreed timelines.
- Acknowledgement and appreciation notes and emails are written to the relevant authorities highlighting that previously identified challenges have been resolved and that service delivery is efficient. There will be no further follow up unless the resolved challenge(s) re-occur.

Periodic (monthly, quarterly, and annual) reviews of the CLM mechanism should be used to monitor implementation progress, identify, and resolve challenges and continue to adapt the CLM mechanism.

Participatory annual reviews by CLM implementing organizations and service users are particularly recommended. Reviews provide a good opportunity for end beneficiaries and communities to appreciate CLM and their power as influencers or positive change makers. Reviews provide an opportunity to document best practices, lessons learned and inform future programming for CLM mechanisms.

3.8   Costing of CLM Mechanisms

Detailed costing of CLM mechanisms is important since it will ensure adequacy of funding. Ultimately, the costing will be informed by the nature, type, and scope of the mechanism. The CLM conceptual framework described in this section may be used as a reference for what should be costed. Specific guidance for costing CLM mechanisms is detailed in the table below.

Activity-based costing should be used as a primary method to estimate the financial costs of implementing the mechanism over a defined period of time. Activities should be costed annually and broken down in quarters to make them easier to monitor, and to synchronize between different calendars and donors. The costs for each activity are estimated as the actual costs of the service or product; or in the case of people, the number of people expected to receive the service multiplied by the unit costs of that service

Where unit costs are not readily available in terms of prices, and the service has been performed previously, the total costs of the services may be divided by the number of people to find out the cost per person, and this cost multiplied to ascertain totals. Specific guidance for costing CLM mechanisms is detailed in the table below.

COST ITEMS / ACTIVITIES	UNITS	NUMBER OF UNITS	UNIT COST IN $	TOTAL COST IN $
I – COMMUNITY EMPOWERMENT AND ORIENTATION				
1.1 Supporting CBOs and networks to communicate	Communication and admin costs	Number of groups		
1.2 Supporting communities to meet up and be sensitized	Cost Per person	Number of people meeting		
II - PLANNING AND CONCEPTUALIZATION				
2.1 Planning and conceptualization meetings CLM mechanism (between 2 and 4 days; select items that apply from the below list)	days	4	XX	
2.1.1 Transport refunds				
2.1.2 Lunch				
2.1.3 Meeting package (2 Teas & 2 waters)				
2.1.4 Per diem for participants / accommodation				
2.1.5 Printing/ stationery				
2.1.6 Meeting hall, LCD and public address system hire				
2.1.7 Communication allowance for meeting coordinators				
2.2 Technical support (technical consultancy fees per day if required)	days	15		
2.3 Travel, & DSA for representatives of communities and key stakeholders				
2.4 Conceptualization meeting (3-day residential retreat with select representatives of communities and key stakeholders, and TA for 20 pax)				
2.4.1-2.4.X – Same assumptions as meetings in 2.1. above				
SUB-TOTAL				
[1]**III - HUMAN RESOURCES[1] - REMUNERATION**				
3.1 CLM Project Coordinator – for the duration of the CLM mechanism				
3.2 CLM Support Officers – 1 for each CLM site				
3.3 M & E, Reporting and Learning Officer				
3.4 IT and Internet / Data base security support				
[2]3.5 Data collectors[2] monthly stipend				
SUB-TOTAL				
IV – STAKEHOLDER MAPPING AND ENGAGEMENT				
4.1 Rapid mapping of key stakeholders in each CLM site location (s)				
4.1.1 Research data collectors	Per researcher per day			
4.1.2 Meeting to validate information on sites and contacts				
4.2 Constitute and make functional steering committee	Committee members			

4.3 Steering committee orientation workshop				
4.4 Monthly Steering committee and communities' meetings	As per 2.1 above			
4.5 Launch materials				
4.6 Community Launch – tents, refreshments & transport where applicable				
SUB-TOTAL				
V - CAPACITY AND BUILDING, DEVELOPMENT OF TOOLS				
5.1 In-depth orientation of all staff and community data collectors				
[3]5.2 Development / procurement of real time data collection software/apps[3]				
5.3 Purchase of data collection gadgets & their configuration				
5.4 Training of data collectors and simulation exercises for the software/apps and gadgets				
5.5 Ongoing Technical support and security for the software (6 months)				
SUB-TOTAL				
VI – DATA COLLECTION, ANALYSIS AND REPORT				
6.1 Stipends for data collection				
6.2 Communication and internet connectivity costs for data collectors				
6.3 Ongoing technical support provided by software/app developers (4.5), IT support (2.4) and CLM support assistants (2.2).				
6.4 Procure data processing computers and their respective software				
6.5 Monthly data review meetings to triangulate and validate the reports (select data collectors, CLM support assistants, coordinators)	Meetings costs as per 2.1 above			
6.6 Design and layout/ desktop publishing for reports and Printing of info graphs of quarterly reports				
6.7 Quarterly Steering committee meetings to share quarterly reporting and agree on an advocacy strategy				
6.8 Design and layout and printing of annual reports				
SUB-TOTAL				
VII - INFLUENCING AND ADVOCACY				
7.1 Community /facility level dissemination and feedback meetings and meetings to agree on an advocacy agenda	Meeting costs as per 2.1 above			
7.2 Quarterly dissemination and feedback meetings	Meeting costs as per 2.1 above			
7.3 Dissemination of quarterly reporting to all stakeholders				
7.4 Budget to support the follow up and implementation of agreed upon corrective actions				
7.5 Budget for multi-level advocacy meetings	Meeting costs as per 2.1 above			
SUB-TOTAL				
VIII- REVIEWS				
7.1 Quarterly review meetings	As per 2.1 meeting costs above			
7.2 Annual review meetings and report	Meeting costs as per 2.1 above			
7.3 TA for annual report				
7.3 End of project evaluation and report				
SUB-TOTAL				
GRAND TOTAL				

PART IV

PART IV CLM: LESSONS FROM FOUR COUNTRIES

To inform the development of this guide, online and face to face interviews were undertaken with implementers of CLM mechanisms from the Democratic Republic of Congo (DRC), Malawi, Tanzania, Uganda, and Zambia. The five case studies provide a snapshot of their respective CLM experiences and lessons learned.

4.1 Lessons from Malawi

Pakachere Institute for Health and Development

Pakachere Institute for Health and Development (Pakachere) is a national NGO based in Lilongwe, Malawi. It supports HIV prevention, care, and treatment among female sex workers. Pakachere previously worked under the Linkages Project and is now receiving direct USAID support through the Local Endeavors programme.

Pakachere's community-based monitoring takes the form of a client satisfaction survey. Under this CLM mechanism, Pakachere utilizes peer educators drawn from active Female Sex Workers (FSWs) who have been oriented to observe and document issues affecting the quality of services at both Drop in Centres (DIC) and health facility level. The FSW peer educators do not interview service users, and only document their respective personal experiences whenever they access services either at the DICs or health facilities. They provide feedback on a set of questions linked to the client satisfaction survey, which are thereafter processed on a quarterly basis by Pakachere and utilized for advocacy and program improvement at all levels. In health facilities, action plans responding to identified challenges are jointly developed and agreed upon by the health facility and Pakachere staff. Unfortunately, the community members i.e. the FSW peer educators are not involved in the analysis and use of the information that they contributed to. Whereas this model is now implemented in four districts, Pakachere has not developed a consolidated quarterly report of the four districts where the CLM mechanism is implemented. There is no consolidated patient satisfaction survey showing the full range of issues affecting FSWs, which would be useful for higher-level advocacy. Follow up has not been structured to ensure that the agreed upon improvements and action plan are implemented.

Despite these and other challenges facing the client satisfaction survey, such as underfunding and limited access to technical support, the CLM mechanism has been beneficial to the community. Key improvements and changes made because of the client satisfaction survey include:

- Improved services by identifying and addressing human rights issues for FSWs
- A significant drop in the numbers of FSWs accessing services at Mangochi DIC was investigated through the CLM mechanism. It was identified that a key staff member had negative attitudes and stigmatized the FSWs. Pakachere undertook corrective action including the re-orientation of all its staff.
- Increased access to ART refills: FSWs are mobile populations and often find themselves in new towns without any medication. When they visit a clinic, they are asked for a health passport to access ART. Subsequent engagement with health facilities removed this requirement, and they now only require their ART number to obtain treatment refills.
- Improved partnership and collaboration between health facilities, CSOs and the community: This has been observed when discussing challenges caused by SGBV and GBV, including the long wait time and sub optimal management of cases. Health facilities now have a focal person based there, whose roles are shared widely within the FSW community, at DIC level and with community members, and at the hospital. GBV survivors now access treatment, psychosocial support, and treatment services in a more structured manner. As service beneficiaries, FSWs are increasingly empowered and can voice their concerns whenever the quality of services is compromised.

> " FSWs are often mobile, and in some instances, they find themselves new towns without any ART. When they go to a health facility, they are told to bring a health passport in order to access ART. Subsequent engagement with the health facilities resulted in facilities only requesting FSWs to share their respective ART numbers in order to get treatment refills!
>
> *Grace Kumwenda, Programmes Coordinator, PAKACHERE*

4.2 Lessons from Sierra Leone

The Experience of Civil Society Movement Against Tuberculosis (CISMAT)

Civil Society Movement Against Tuberculosis (CISMAT) is national CSO based in Sierra Leone. With Gobal Fund support, CISMAT is implementing a CLM mechanism focused on improving the quality of services for TB patients. The CLM is a nationwide mechanism, implemented in all of the country's 16 districts, and in more than 170 TB facilities.

The CLM mechanism was designed to facilitate improvements in access to and quality of TB services; promote social accountability

> " 140 community members drawn from TB survivors, civil society and human rights activists were trained as Community TB animators (CTAs). 10 -12 CTAs are deployed in each district with 1 CTA attached to each of the 170 DOT/health facilities. The CTAs' main role is to monitor and follow up on TB services delivery at health facilities and communities on a monthly basis using paper-based CLM feedback tools
>
> *Paul Bangura,*
> *Ag. Executive Director*

and Value for Money (efficiency, effectiveness, equity, sustainability, and economy) in TB services. This is because demand for TB services was low, with many cases of loss to follow up (LTFU), while patients were paying for services that should have been free of charge. In addition, some facilities were not well equipped to provide services and patients travelled long distances to access treatment, faced stigma and discrimination and were often sent back home due to medicine stock outs.

Through Global Fund support, up to 140 community members drawn from TB survivors, civil society and human rights activists were trained as Community TB Animators (CTAs). Between 10 and 12 CTAs have been deployed in each district with 1 CTA attached to each of the 170 DOT/health facilities. CTAs' main role is to monitor and follow up on TB service delivery at health facilities and communities every month using paper-based Community Led Monitoring and Feedback (CLMF) paper-based tools. The information is submitted to the district coordinator (s) for onward submission to CISMAT. Data analysis and synthesis is undertaken manually, and reports generated every six months.

In delivering the CLM mechanism, CISMAT has faced several capacity related challenges including inadequate capacity in CLM, communication and dissemination of CLM reports and delays in submission of reports. On the other hand, significant

improvements have been noted because of the CLM mechanism. These include stronger partnership and collaboration between the TB community and the national public sector program (NLTCP). Communities and CSOs are more meaningfully engaged in Global Fund grant implementation and the national response. TB patients and survivors are empowered as ambassadors in their respective communities, and now know where to raise complaints regarding service delivery. Since implementation of CLM began, communities have gained a deeper understanding of community led CLM mechanisms, while demand for TB services has increased, and number of cases lost to follow up is decreasing along with instances of stigma, discrimination, and commodity stock outs.

4.3 Lessons from Zambia

The Centre for Infectious Diseases Research in Zambia (CIDRZ) Experience

The Centre for Infectious Diseases Research in Zambia (CIDRZ) is a national NGO based in Lusaka. CIDRZ implemented its CLM mechanism as a part of PEPFAR's Achieving Epidemic Control Program (ACHIEVE) accelerating progress towards 95-95-95 targets. The mechanism was launched in three health facilities within a district in Zambia's Western Province. Prior to this, CIDRZ had implemented the Patient Centered Health Care for HIV program, and others which earned it significant CLM experience.

In this project, CLM focused on large hospitals serving many people, and significant contributions to testing, enrolling people on ART and measuring viral load. At the start of the project in April 2019, Senaga General Hospital had a total of 2850 patients, out of whom only 400+ were virally suppressed. The community led (PLHIV) CLM mechanism used clients' feedback to better understand challenges affecting HIV management and address barriers to viral load suppression so that better interventions could be designed.

During startup, consultations were held on HIV prevention, care,

LESSONS LEARNED

i.   Dedicated and adequate funding to CLM is key. Current funding mainly covers data review and stakeholder engagement meetings. In addition, community members who double up as data collectors cannot undertake this work on a voluntary basis. With adequate funding, investments will be made in strengthening data collection, analysis, feedback, and advocacy.

ii. CLM is time consuming and needs dedicated staff / teams who can be fully engaged in this work and not have to split their time with other often competing tasks.

iii. Comprehensive training and orientation of communities and stakeholders on CLM is essential.

iv. It is important for CLM mechanisms to be flexible to routinely adapt to the dynamic context and the needs of the communities

v.   Advocacy must be planned and budgeted for. This is because some findings made through a CLM mechanism cannot be resolved effectively at facility level.

Dr Mainza Bubala, CIDRZ

and treatment, while research investigated problems in service delivery and adherence to treatment. A working group was established to develop a CLM model that considers the local context and few available resources. CIDRZ sensitized and oriented the community, health care workers the ART clients, held planning meetings with the community members, health facility personnel and the District AIDS Coordinator's Office.

Currently, community members administer the paper-based questionnaires/ score cards on service program indicators to fellow beneficiaries at both family and community level. Data collection is routinely done depending on indicators (Daily, weekly, or monthly) with monthly and bi-monthly analysis of collected data. Information is submitted, analyzed, and processed during monthly feedback meetings with facility staff and key stakeholders. The analysis is manual, and looks at each completed questionnaire, validating the feedback. Physical counting and tallying of responses are done. The overall assessment reports are generated quarterly while monthly/bi-monthly assessment reports are produced covering specific indicators and issues to assess the impact of actions undertaken. In less than 12 months, positive results were observed, including increased service acceptability by clients and reduced wait times for unsuppressed clients.

 Following introduction of a separate High Viral Load (VL) clinic, staff attitudes have improved, and become professional and client-centered. In addition, more staff were attached to the ART department following lobbying. VL coverage improved and the facility achieved around 98% VL suppression, up from 88% after only 4 months of implementing the CLM mechanism. Improved retention of High VL clients through the extensive adherence process was also realized. Lessons learned from this pilot CLM mechanism were that:

i. Dedicated and adequate funding to CLM is key. Current funding mainly covers data review and stakeholder engagement meetings. In addition, community members who double up as data collectors cannot undertake this work on a voluntary basis. With adequate funding, investments will be made in strengthening data collection, analysis, feedback, and advocacy.

ii. CLM is time consuming and needs dedicated staff / teams who can be fully engaged in this work and not have to split their time with other often competing tasks.

iii. Comprehensive training and orientation of communities and stakeholders on CLM is essential.

iv. It is important for CLM mechanisms to be flexible to routinely adapt to the dynamic context and the needs of the communities

v. Advocacy must be planned and budgeted for. This is because some findings made through a CLM mechanism cannot be resolved effectively at facility level.

4.4 Lessons from Uganda

Uganda is one of the countries with the longest and most diverse experiences of implementing CLM in the region. This case study is a summation of the experiences from CLM mechanisms implemented in Uganda under a range of diverse implementers.

Coalition for Health Promotion and Social Development (HEPS Uganda)

The Coalition for Health Promotion and Social Development (HEPS Uganda) works with diverse community level service users. HEPS CLM mechanism seeks to form and strengthen a team of well empowered district level service recipients (bringing in a diverse range of clients) to monitor service delivery. These include at least 10 people (expert clients, women living with HIV, young people (boy and girl), key populations (KPs) namely female sex workers (FSWs), men which have sex with men (MSM) and Lesbians, Bisexual, Intersex, Transgender and Queer (LBITQ), people living with disability,

men and TB focal persons who are trained and mentored by the national team in different dimensions. They hold quarterly meetings that would feed into CSOs' meetings at national level, conduct quarterly assessment using the community scorecard or any other tools designed by the leadership. Data collection is paper based. Information is collected through direct observation of facilities by community monitors, surveying clients at facilities, interviewing staff, and managers, conducting focus group discussions and through door-to-door surveys in communities served by clinics. HEPS has been seeking additional funding from COP and others to digitize their CLM mechanism. The information is then translated into actionable decisions in group discussions and interpretation sessions which identify problems and make recommendations Dissemination and advocacy is undertaken by stakeholders at all levels including implementing partner meetings at regional and national level, funding partners, the Ministry of Health (MoH) Technical Working Groups (TWGs) and national civil society networks. All these provide near real time updates on service delivery and monitor implementation of the action items by service providers. The information collected also feeds into the Peoples Country Operational Plan (COP) for Uganda.

Limited funding for the CLM mechanism still poses challenges. HEPS has also realized that their reports could be better visualized through a dashboard that also provides real time information.

The Uganda Network of Young People Living with HIV AIDS (UNYPA)

The Uganda Network of Young People Living with HIV AIDS (UNYPA) helps improve access, demand, and quality of health services among young people. UNYPA utilizes scorecards in its CLM mechanism.

The CLM mechanism was designed collaboratively by implementing partners of the SRH&R alliance in the broader Get Up Speak Out (GUSO) Program. Communities and service users were not only involved in actual data collection but also contributed to its analysis, resulting in the development a concept note and budget for the project. Other activities included planning and sensitization meetings, community mobilization and training of data collectors drawn from the community of young people.

This was followed by data collection by community members on access and quality of services by young people living with HIV including AGYW and the youth. The data was subsequently analyzed using scorecards.

Dissemination of CLM findings was mainly through feedback meetings with the health facility in charge, management teams, and during district health coordination meetings. The findings were also shared with Youth Alliance members, service providers, district health teams and funding partners. CLM findings shared in several meetings.

Key outcomes and improvements attributed to the CLM mechanism include improved provision of youth friendly services, and improved quality of services, while young people are recognized and prioritized during clinic visits. Youth friendly structures were also set up within clinics to enhance demand by other youth at Jinja Referral Hospital, which now boasts a well-equipped youth center, and other areas. Other positive results included improved capacity among community members to identify gaps and recommend informed advocacy actions; friendlier service providers; a significant reduction in stock outs and enhanced working partnership between young people, the district leadership and health service providers. Key innovations include the use of young champions and peers as data collectors and advocates; and the training of community paralegals who now support and link services youth in communities to legal services.

Key gaps in the CLM mechanism include inadequate engagement with other implementing partners, lack of clear CLM indicators to guide the collection of relevant information, slow data sharing by district level partners, and the limitations in human resources.

Key lessons learned were that it is important to provide timely feedback to address bottlenecks and to be objective (without bias) at all times. The project has shown that it is possible to ensure that 'no one is left behind', especially the youth. The CLM mechanism was implemented over a period of one year with support from AIDSFonds.

4.5 Lessons from the Democratic Republic of Congo (DRC)

Club des Amis Damien

Club des Amis Damien (CAD) is a national CSO based in DR Congo. With support from the Stop TB Partnership, under the Strategic Initiative to Find the Missing People with TB, CAD with the strategic guidance from the National TB Control Programme (PNLT) is implementing community-based monitoring using OneImpact.

What is OneImpact? The OneImpact platform is a digital CLM monitoring alert system. When services are not available, accessible, or of poor quality, people affected by TB can notify community and formal health systems using an APP in real time. Once reported the integrated feedback loop mechanism automatically informs community (first) responders and national TB programs of current gaps in service provision via a Dashboard so that they can rapidly respond and monitor trends, to close the gap in the number of people who fail to receive TB care and to advance UHC goals, the right to health and accountability in the TB response.

How does it work? PNLT and CAD adapted, and pilot tested the OneImpact CLM intervention between December 2018 – December 2019. They used and followed an implementation science-based approach and the phases recommended by World Health Organization in the Handbook on Digital Technologies for TB, namely; feasibility and needs assessment, adaptation, solution development, training and launch, data collection and solution maintenance and monitoring and evaluation. The needs and feasibility assessment revealed that duty bearers and not always aware of the link between human rights, TB and accountability, right holders are not aware of their human rights in the context of TB or how to claim them and that accountability mechanisms that would allow people to report barriers and claim their rights, while holding those to account were not available. Based on these gaps PNLT and CAD adapted the Stop TB Partnership OneImpact CLM framework and digital solution with the engagement of the affected community. The affected community identified several barriers under the AAAQ (availability, accessibility, acceptability and quality) framework, which were incorporated into the APP along with appropriate and easily understood information on TB prevention, treatment and care to support people along the TB journey. Based on the information provided by the TB affected community PNLT and CAD designed CLM indicators, which aligned with their strategic priorities in the National Strategic Plan. In June 2019 CAD and PNLT finalized the platform, launched OneImpact TB Tolongi and trained people affected by TB, community health workers (first responders) in the CAD network and nurses and heads of health facilities. Data collection commenced in July 2019.

Results: By December 2019, the intervention revealed that 46% of people with TB involved in the intervention had faced (reported) at least one barrier. The intervention also revealed that 89% of barriers reported related to the quality of services but that people also faced barriers of availability, affordability, acceptability, and access.

Proportion of People Experiencing Barriers

89% OF PEOPLE WITH TB REPORTED BARRIERS TO DO WITH THE QUALITY OF TB CARE AND SUPPORT SERVICES AT LEAST ONCE

45% OF PEOPLE WITH TB REPORTED BARRIERS TO DO WITH THE AVAILABILITY OF TB CARE AND SUPPORT SERVICES AT LEAST ONCE

30% OF PEOPLE WITH TB REPORTED BARRIERS TO DO WITH THE AFFORDABILITY OF TB CARE AND SUPPORT SERVICES AT LEAST ONCE

29% OF PEOPLE WITH TB REPORTED BARRIERS TO DO WITH THE ACCEPTABILITY OF TB CARE AND SUPPORT SERVICES AT LEAST ONCE

21% OF PEOPLE WITH TB REPORTED BARRIERS TO DO WITH THE ACCESSIBILITY OF TB CARE AND SUPPORT SERVICES AT LEAST ONCE

CBM Timeframe: 01-Jul-2019 to 27-Dec-2019

When each barrier category under the AAAQ framework was broken down, (based on what was reported by people affected by TB) CAD and PNLT could clearly identify the root causes of the barriers, which in the case of affordability was poverty and a breach of policy. Under acceptability, people also reported that TB stigma in family (29%) and health care (23%) settings was particularly problematic.

Breakdown of Affordability Issues

% of Issues Reported on Affordability

- I had to pay for transport to get to the health center
- I had to pay for an appointment
- I had to buy food in order to take my medicines when I can't afford it
- I had to pay for ancillary drugs to address my treatment side effects
- Other

27% 22% 21% 19% 11%
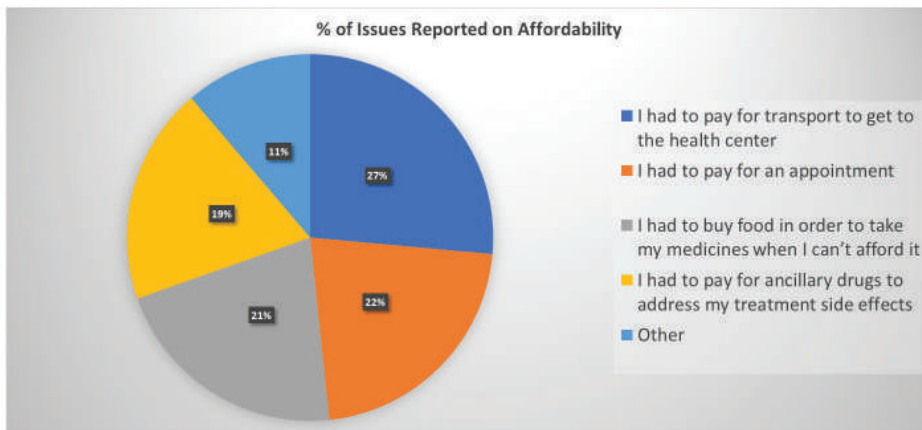
CBM Timeframe: 01-Jul-2019 to 27-Dec-2019

How was the data used? At an individual level CAD First Responders demonstrated that they could validate and coordinate a response to all problems reported within a week. At a health systems level, PNLT and CAD used the data to inform and develop the National Strategic Plan (NSP) and the Global Fund funding request. Addressing human rights and gender barriers with a focus on TB key and vulnerable populations are now strategic and priority focuses of the NSP and activities to address them are included in the GF Funding Request, including the institutionalization of the CLM OneImpact TB Tolongi intervention.

User satisfaction? The comparative results of the baseline and end of project assessment revealed that all 3 users (person with TB, community health worker, PNLT) recommend the platform from their perspectives.

What were the lessons learnt to inform scale up?

Lessons Learnt

- Progressing UHC and ending TB by 2030 depends on transformed health systems that include significantly scaled-up community responses.
- CBM OneImpact TB Tolongi is driving the goal of UHC, the right to health and social accountability in the TB response in DRC.
- CBM OneImpact TB Tolongi provided an opportunity to have a dialogue at all levels of the TB response on human rights and TB in DRC.
- Knowing your Rights is a core component of the intervention. Intense and ongoing Know Your Rights trainings is essential to CBM in DRC.
- The OneImpact CBM platform is flexible and can be adapted to meet local needs, such as local language incorporation, data storage, privacy and confidentiality.
- The electronic collection of data has the potential to allow DRC to easily access and analyze data for large scale programmatic decision making.

MORE INFORMATION?

Stop Partnership CLM Investment Package

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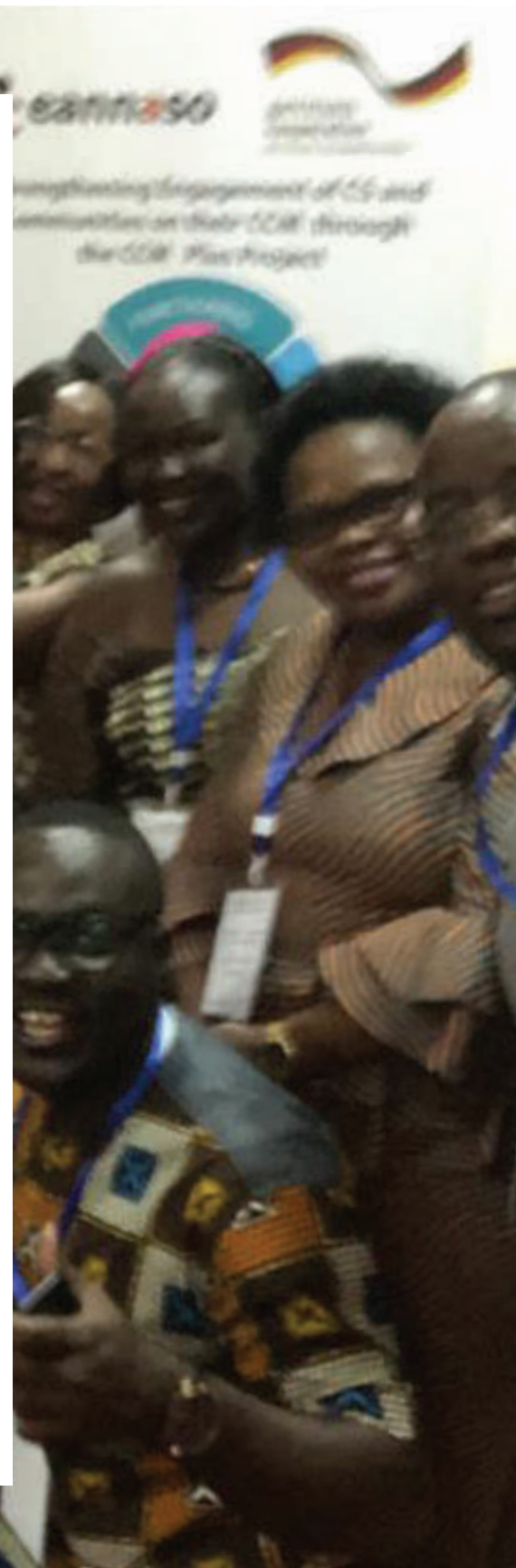
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