

COMMUNITY-LED MONITORING AND ENGAGEMENT FRAMEWORK FOR HIV/TB & SRHR SERVICES

*TOWARDS “INCLUSION AND INVOLVEMENT”, “INPUT AND INFLUENCE” OF PLWH AND KPS IN NATIONAL HIV/TB
AND SRHR POLICIES AND PROGRAMS.*

Community Actions for Change

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List of Acronyms

AAAQ Availability, Accessibility, Acceptability and Quality

COP Country Operational Plan

CSOs Civil Society Organisations

HIV Human immunodeficiency virus

PLWH Persons Living With HIV

TB Tuberculosis

SRHR Sexual Reproductive Health and Rights

WHO World Health Organisation

1.0 Introduction

As Uganda works to achieve HIV epidemic control, the scale-up of high-quality patient centered HIV/TB and SRH services for persons living with HIV and key populations is critical. Placing communities and patients at the center of the HIV response is critical to controlling the HIV epidemic. Community engagement has been identified as a key pillar to successful and sustainable HIV/TB and SRHR programs. The participation of people living with HIV, including recipients of care and their advocates, in the design, implementation, and evaluation of HIV/TB and SRH initiatives is critical to assure both demand from people living with HIV, key populations and supply of high-quality, contextually appropriate services. The WHO has defined community engagement as “a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes.” Health systems in Uganda have embraced community engagements though in a more adhoc way through health unit management committees and village health teams. However, the gap with existing committees is the lack of a structured way of generating feedback and carrying on engagements within the structure of the health system from community-health facility-district-district to national level. This community engagement framework presents a latent opportunity to build and strengthen mechanisms through which persons living with HIV can play a critical role in shaping not only availability, accessibility, acceptability but as well quality of existing HIV/TB and SRHR services. This engagement framework provides a coherent process that links a focused HIV/TB and SRHR monitoring tool to meaningfully developing a constructive dialogue with duty bearers from local government to national-global levels and aligns them in a way that leads to changed conditions and systems for better and effective HIV/TB and SRHR services for PLWH. The community feedback will be used to initiate changes inside the health system and potentially optimize system performance, lead to better-quality, safer HIV/TB and SRHR services for persons living with HIV so as to achieve improved health outcomes at the individual, community and population level. As a practical resource it provides a clear definition of community engagement and importantly sets specific standards for community engagement that all Partners must adhere to. It identifies the first wave of priority actions that must be taken to improve community engagement in the city

1.1 Background

For a long time, traditional approaches to engaging service users, affected families and local communities have broadly focused on better information provision and the improvement of communication between service users and service providers. While on the service user side, the focus has tended to be on empowering patients, families and communities

to be more literate in using and navigating the health system, as well as working through representation and mechanisms to improve accountability of health systems.

Often, the perception of quality of care is shaped by relational and contextual factors and not necessarily the efficacy or safety of clinical or technical interventions alone. Despite these observations, traditional approaches have missed important opportunities to improve quality by ignoring how culture and context shape not only the relationships between people, but also how the outcomes of these relationships and human interactions influence the way that health services and health care are organized, delivered and experienced. Consequently, patient-provider interaction continues to be sub-optimal across, high-, middle- and low income countries. At the same time, national health programmes ranging from HIV/AIDS, immunization, and malaria to sexual, reproductive, neonatal, child, adolescent and mater-nal health, routinely struggle to engage with communities in ways that factor in their needs, builds trust and ensures that programme objectives and health outcomes are reached, in a sustainable way.

Improving the quality of HIV/TB health care and SRHR services to better deliver on treatment outcomes remains a key challenge to the 2030 global HIV agenda. Service users and patient's experiences and feedback on programs and services remain a key tenet of not only assessing if services are meeting the needs and expectations of user but as well develop a shared understanding of the enablers and barriers to treatment retention in a manner that is productive, collaborative, respectful, and solutions-oriented. PEPFAR particularly has recognized the important role of patient's experience with HIV/TB programs and civil society organizations participating in the COP strategic planning meetings will be asked to present the vision, principles, tenets and recommendations of community-led monitoring (for their country) during the meeting.

1.2 Why this Community Engagement Framework matters.

The Community-Led monitoring and Engagement Framework provides impetus to identifying and addressing common experiential barriers and challenges faced by PLWH and key populations to access, availability, acceptability and quality (AAAQ) of HIV/TB and SRHR services and to co-create solutions in HIV/TB and SRHR programs. The Community-Led Monitoring and Engagement Framework identifies key levels of engagement, stakeholders to target and defines actions that PLWH and KPs can undertake to shape HIV/TB and SRHR policies and programs. The framework provides guidance on how who and when to undertake engagement, steps and processes should be considered to effectively engage health systems for better services. The document will as well support ministries of health and their partners to engage people living with HIV in HIV/TB and SRHR responsive programs meaningfully.

1.3 Rationale for the CLM Community Engagement Framework.

The Community-Led Monitoring and Engagement Framework has been developed to be both a policy and program influencing/strengthening framework for especially HIV/TB and SRHR services taking into consideration the governance process for service delivery at community, district, national and global levels. The framework provides practical guide for persons living with HIV (PLWH) and key populations to get *included and involved*, “*make input and influence*” national HIV/TB and SRHR policies and programs have a voice to influence issues of availability, accessibility, acceptability and quality (AAAQ) of HIV/TB and SRHR services. This document stimulates the inclusion of Community-Led Monitoring and Engagement to complement national monitoring systems, identify bottlenecks to improve service delivery and respond to community preferences regarding access, quality and acceptability of services. The framework maps out key decision making forums, identifies stakeholders at each forum and elaborates how persons living with HIV and key populations can constructively engage to achieve responsive HIV/TB and SRHR policies and programs. It further seeks to maximise opportunities for persons living with HIV, Key populations and communities affected by HIV/TB and poor SRHR outcomes to take control over the issues that affect their lives and use them to shape the way services are designed, planned, implemented and reviewed. The Community-Led Monitoring and Engagement Framework will be truly independent, community-led and owned, building on approaches that are delivering impact and ensuring robust advocacy and watchdogging

1.4 Purpose of this Community Engagement Framework.

This framework lays a firm *foundation towards “inclusion and involvement, input and influence”* of particularly persons living with HIV and key populations to shape HIV/TB and SRHR policies and programs. It provides a unique opportunity for communities and service providers to collaboratively improve quality and efficiency of investments, particularly for key and vulnerable population prevention, care and treatment programs. The framework deliberately anchors CSO and partners program investments into the capacities of PLWH and key populations to be active participants in policies and programs that seek to achieve the HIV/TB epidemic control or SRHR services, promoting an interdependent and constructive engage with duty bearers across all levels. The framework identifies key moments and stakeholders to deliberately target at community, local government, national and global level responsible for making decisions around HIV/TB and SRHR.

1.5 Principles of Community-Led Monitoring and Engagement

The framework will be guided by the standards for community engagement, of community empowerment, *inclusion and involvement*, *“input and influence of PLWH and key populations in shaping how HIV/TB and SRHR policies and programs are designed, planned, implemented and evaluated*; Specifically, this engagement framework is anchored within the following principles;

- **Focus on Empowerment of the community;** Persons Living with HIV (PLWH), Key Populations (KPs) and communities affected by HIV will be empowered to execute most of the roles in the community engagement framework. Specific trainings shall be organised in areas of community led monitoring, participation in planning and budgeting, advocacy and communication, community mobilisation and engagement.
- **PLWH and KPs Community centred and driven;** significant decision-making will be placed in the hands of the community as key beneficiaries of the services to increase engagement between communities and public bodies, taking action themselves, ensuring that concerns and aspirations are consistently understood and taken into consideration by duty bearers at various layers of government.
- **Community involvement, participation and inclusion;** PLWH and Key populations will be capacitated to drive processes at community, health facility, and district levels. Through these communities driving the processes and taking action, categories like key populations and PLWH who experience both increased impact from one or more of the diseases and decreased access to services will take action to demisify stigma and discrimination, state and non-state violence and harassment, restrictive laws and policies, and criminalization of behaviors or practices put to key populations.
- **Sound Integrity, transparency and accountability towards the community;** Community engagement being open and honest and having integrity and ensuring all community engagement activities have clarity of purpose and make a difference. Engagement will be clear and transparent to ensure the community has access to all the necessary information and understands the processes and resources involved.
- **Evidence Base;** In the response to HIV, like any other response to a development or health challenge, the evidence base is critical. Engagements will be informed by the assessments conducted by persons living with HIV and KPs. Reports shall be consolidated and used for engagement at various layers of government and decision making. Effort will be made to nurture individuals within the community to technically present the findings to various stakeholders

- **Feedback, Learning and adaptation;** that CLM processes will be reviewed regularly and that we together with the community will strengthen learn from our work processes to improve practice wherever we can and build a body of knowledge for others.

How does Community-Led Monitoring and Engagement framework add value to HIV/TB and SRHR programs?

- Contributes to the attainment of the HIV 95X95X95 treatment cascade success by maximizing impact of interventions against HIV, TB and SRHR, community resilient and sustainable systems and protect human rights of PLWH and KPs.
- It helps collect, assess and triangulate data and observations both quantitative and qualitative that are essential for program continuous improvement, oversight of HIV/TB and SRHR policies and programs
- Provides opportunity to fill gaps in HIV/TB and SRHR issues that cannot be captured by formal health information management system for example it can uniquely find people who have dropped out of care to provide insights for how overall retention efforts might be improved.
- Can provide a body of live experiences of PLWH and KPs and advocacy knowledge to shape future HIV/TB and SRHR programs for communities bringing community-led solutions to address program implementation bottlenecks, quality and performance to the table.
- It is an essential component of entrenching human rights and community participation in HIV/TB prevention, care and treatment programs and other SRHR services

2.0 Goal of the Community-Led Monitoring and Engagement Framework

Enable better HIV/TB and SRHR service user informed decision-making by utilizing local, cultural, experiential and situational knowledge of PLWH and KPs.

2.1 The aims of this framework should be:

- Ensure community views are understood by all implementing partners and public bodies providing HIV/TB and SRHR services
- Ensure the community has the opportunity to participate in the CML through inclusive and equitable engagement practices.

- Strengthen community connectedness by creating opportunities for the community to get involved with, and have their say on, matters which are important to them.
- Improve the relationship and level of trust between the community and PEPFAR by ensuring the community is informed about and involved in PEPFAR activities.
- Enhance the coordination, planning and promotion of USG's external engagement community interventions.
- Strengthen feedback and communication from PEPFAR so the community knows when and how their input has been considered to inform decisions.

3.0 Levels of engagement

To move towards the overall goal of the National Strategic Plan (2015 – 2020) of moving towards Zero new infections, Zero HIV and AIDS related mortality and morbidity, and Zero discrimination, engagements at all levels of governance are necessary targeting key decision makers and program implementors. Involvement of communities/PLHIV and KPs has been documented as a key best practice in HIV response especially with community systems strengthening to support mobilization, retention, adherence and psycho-social support. These have contributed to the success of the program. Learning from this model, the framework is designed to provide an additional role of PLWH and KPs to influence duty bearers within the whole chain of governance.

Individual level – at this level effort will be geared towards building the capacity of persons living with HIV and key populations to know their health rights and responsibilities in the health system and HIV treatment cascade. They will be empowered to use community level monitoring tools and service assessments to ensure their voice is considered while designing, planning and implementing HIV/TB and SRHR services. They will be responsible for generating evidence for grassroots, district and higher level advocacy. Key targeted stockholders for empowerment are the persons living with HIV and their networks, key populations individuals and groups

Health facility and community level – Health facilities act as key HIV/TB and SRHR service points for the community. However, we note that over time there have been challenges with issues of commodities, staffing, stigma and discrimination among other services. Effort will be undertaken to routinely assess the continuum of quality HIV/TB and SRHR services at health facilities. These processes will be led by persons living with HIV and their networks and will form a springboard for health facilities engagements on the findings of the assessments of HIV/TB and SRHR services

at health facilities. Key stakeholders targeted for engagement here include health workers, health unit management committees, village health teams and the sub county leadership as an entity that is responsible for over planning for services at the facility level

District level – The district as a higher local government plays a vital role of overall planning and financing of HOV/TB and SRHR services in the district. PLWH and their networks, key populations in liaison with the district HIV/AIDS focal persons will plan and implemented district based engagement meetings on the findings of the health facility assessment of HIV/TB and SRHR services. Key stakeholders targeted for engagement at the district will be the political and technical leaders of the district, any HIV/TB and SRHR district based implementing partners and the local media. Districts will be guided to develop district based remedial action plans for issues identified during the service assessments at the health facilities. Effort will also be made to ensure participation of PLWH and key populations in district planning and budgeting processes as a way of influencing resources for HIV/TB and SRHR in district plans and budgets.

National level – The national level will target to influence HIV/TB and SRHR policies and programs through utilizing experiences of communities to shape how policies and strengthen and programs designed. Additional, PLWH and key populations groups and networks will be encouraged and mobilized to participate in national processes that shape planning and budgeting for HIV/TB and SRHR services in the country.

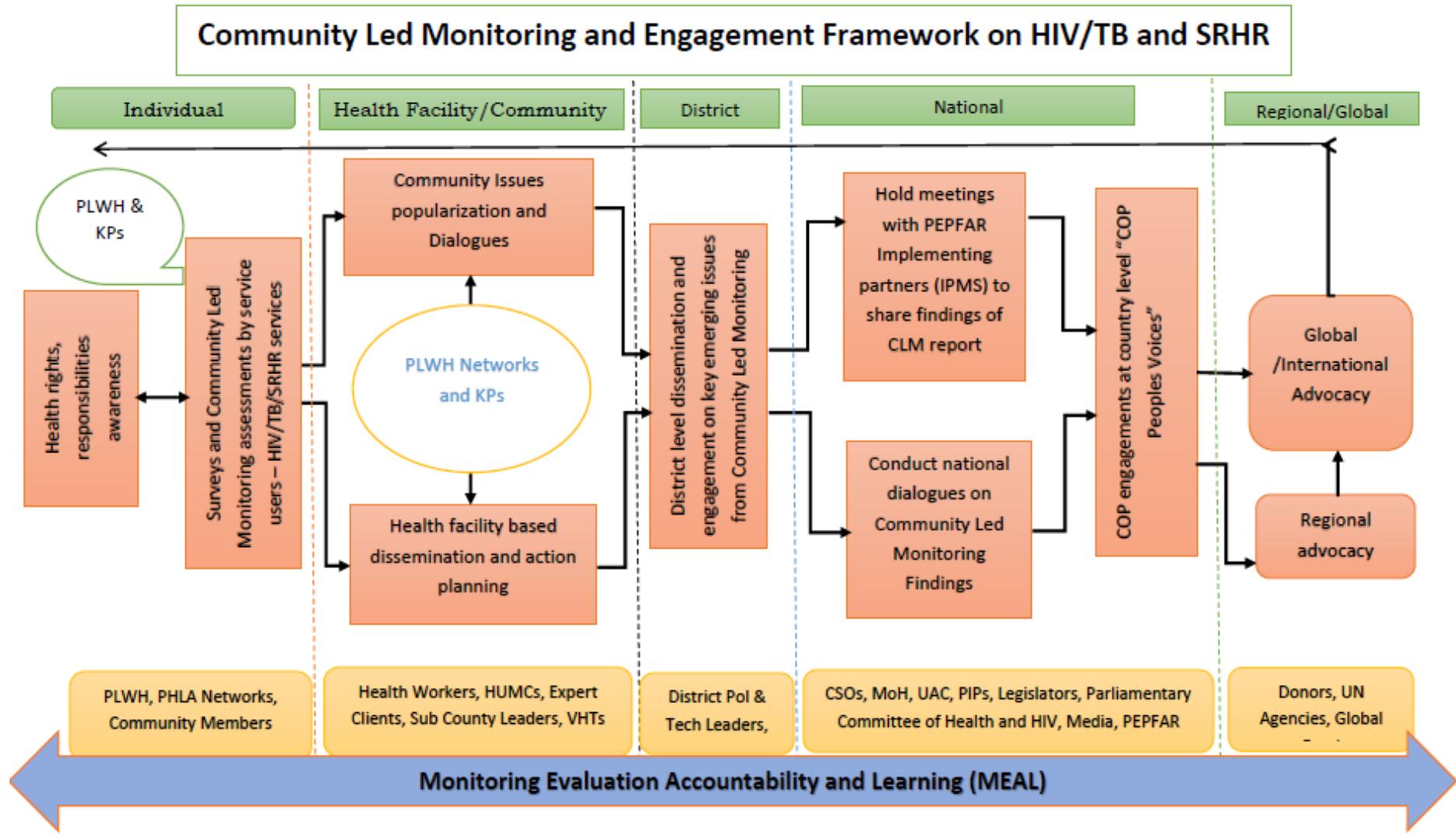
Regional level – At regional levels, the CLM consortium partners shall take advantage of regional level mechanisms to influence bodies like the east African community, inter-governmental bodies.

Global level – Effort will be made to use community experiences with HIV/TB and SRHR programs to engage and influence global mechanisms like the COP processes, global fund processes and UN mechanisms to use community feedback to influence programs around HIV/TB and SRHR

3.1 Key Stakeholders Targeted for Engagement

Levels	Stakeholders
Individual	<ul style="list-style-type: none"> • PLWH • PLWH Networks • Key Populations (KPs) • Persons affected by HIV
Health Facility and Community	<ul style="list-style-type: none"> • Sub County Leaders • Village Health teams (VHTs) • Community based Organisations (CBOs) • Health Unit Management Committees
District	<ul style="list-style-type: none"> • District Political leaders • District Technical Leaders • District HIV focal person • District based PEPFAR IPs
National	<ul style="list-style-type: none"> • Civil Society organizations (CSOs) • PEPFAR IPS • Ministry of Health (MoH) • MoFPED • Uganda Aids Commission (UAC) • Legislators - Parliamentary Committee of Health and HIV • National Media
Regional	<ul style="list-style-type: none"> • East African community (EAC)
Global	<ul style="list-style-type: none"> • Donors • UN Agencies • Global Fund

3.2 Community – Led Monitoring and Engagement Framework Structure



3.3 Community-Led Monitoring and Engagement Framework Strategies

Levels of engagement	Strategic Focus	Policy related actions	Program Related Actions	Stakeholders to target
Individual	Health rights, responsibilities awareness	<ol style="list-style-type: none"> 1. Conduct a quick scoping of key HIV/TB and SRHR policies and programs 2. Profile and develop a rights and responsibilities brief for PLWH and KPs for individual knowledge 3. Popularising existing HIV/TB and SRHR policies 4. Provide simplified and abridged versions of Key HIV/TB and SRHR polices to PLWH and KPs 5. Hold individual discussions and awareness sessions on current key HIV/TB and SRHR policies 	<ol style="list-style-type: none"> 1. Train PLWH networks in community led monitoring 2. Conduct routine training on data collection assessment tool 3. Conduct awareness sessions on health rights and responsibilities and obligations of health workers 4. Mobilize communities and service providers, building on a sense of shared responsibility and solidarity around issues of health and social justice 5. Support people living with HIV, KPs and persons affected by HIV to participation in local level consultations for development of national guidelines and standard operating procedures 6. Encourage people living with HIV and KPs to give evidence and experience with existing 	PLWH KPs Persons affected by HIV

			models of HIV/TB and SRHR services 7. KP Peer educators and other people living with HIV provide ongoing health education to communities	
	Surveys and Community Led Monitoring assessments by service users - HIV/TB/SRHR services	<ol style="list-style-type: none"> 1. Identify and profile key HIV/TB and SRHR policies 2. Review the HIV/TB and SRHR policy commitments specific to PLWH and KPs 3. Design and develop the HIV/TB and SRHR policy scope commitments specific for PLWH and KPs 4. Empower and engage people and communities on the policy commitments 	<ol style="list-style-type: none"> 1. Define the specific service standards/minimum health care package provided for HIV/TB and SEHR services in public facilities 2. Align and develop the HIV/TB and SRHR monitoring tool to the service standards 3. Pre-test the tool at the health facility 4. Train PLWH and KPs to administer the HIV/TB and SRHR monitoring tool 5. Periodically, support PLWH and KPs administer the HIV/TB and SRHR service monitoring tool 6. Support PLWH and KPs to analyse the data collected and generate an easy to use report for engagement 7. Implementing Partners (IPs) support PLWH and KPs community advisory groups 	PLWH KPs Persons affected by HIV

			to develop community level operational plans	
Health Facility/Community	Community Issues popularization and Dialogues	<ol style="list-style-type: none"> 1. Policy roll-out/dissemination planning to communities 2. Develop simple, clear communication materials to facilitate explanation of HIV/Tb and SRHR policies to communities 3. Supporting networks of people living with HIV and KPs to lead actual roll-out of policies in communications and other dissemination forums 4. Advocating for area leaders to budget and allocate resources for HIV/TB and SRHR policy implementation 	<ol style="list-style-type: none"> 1. People living with HIV and KPs supported to conduct community sensitization and demand creation for HIV/TB and SRHR services 2. Host community conversations throughout its local neighbourhoods, providing residents with information about key projects and services 3. PLWH and KPs participate in lower local budget conferences at sub counties 4. Disseminate key findings of the CLM to the lower local government leaders at the sub county e.g. the sub county councils, sub county technical planning committees, Sub county HIV committees 5. Analyze sub county budgets and develop simplified briefs for community advocacy for better funding of HIV/TB and SRHR services 6. Follow up on commitments made by lower local 	Sub County Leaders, VHTs, CBOs

			governments on HIV/TB and SRHR	
	Health facility based dissemination and action planning	<ol style="list-style-type: none"> 1. Plan for CLM report disseminations to health workers 2. Execute the disseminations at health facilities and guide health facilities to develop performance improvement action plans 3. In Uganda, Health facility committees include people living with HIVrepresentatives 	<ol style="list-style-type: none"> 1. Encouraging PLWH and KPs to be part of linkage facilitators of services as co-partners/service providers (CHW, peer educators, ART delivery, VL/DSD champions and/or gate-keepers) 2. Organizing PLWH and KPs to hold dissemination and engagement on CLM findings 3. Guiding health facilities to develop action plans for issues within their mandate 4. PLWH and KPs follow up on commitments made by health workers in the action plan 	Health Workers, HUMCs, Expert Clients
District	District level dissemination and engagement on key emerging issues from Community Led Monitoring	<ol style="list-style-type: none"> 1. Ensure meaningful participation and visibility of district network for people living with HIV, KPs and their advocates in district HIV/TB and SRHR policy level engagements 2. Include people living with HIV, KPs and their advocates in 	<ol style="list-style-type: none"> 3. Invite people living with HIVleaders to join extended district health management teams 4. Disseminate CLM findings to district leaders 5. Develop district level action plans on key issues in CLM reports 6. Follow up and review implementation of key 	District Pol & Tech Leaders, PLHA Networks

		policy validation exercises	commitments made by the district authorities 7. PLWH and KPs participate in local government planning and budgeting processes.	
National	Hold meetings with PEPFAR Implementing partners (IPMS) to share findings of CLM report and other PEPFAR TWG committees	<ol style="list-style-type: none"> 1. People living with HIV and KPs present/submit their needs during Country Operational Plan (COP) guidance meetings 2. Shaping COP plans and budgets for HIV/TB and SRHR 	<ol style="list-style-type: none"> 1. PLWH and KPs present findings of the CLM report to PEPFAR IPs for re-course and action 2. PLWH and KPs participate in COP processes and make input into country plans 	PIPs, PLWHI groups, KP led CSOs, PLH Networks
	Conduct national dialogues on Community Led Monitoring Findings	<ol style="list-style-type: none"> 1. people living with HIV engaged in different programs & TWGs 2. support advocacy efforts towards improved budgeting and allocation of resources for implementation of existing HIV/TB and SRHR policies 3. advocate for ring fencing of PLWH/KP membership position within the Health facility community oversight committees 	<ol style="list-style-type: none"> 1. Capacity building initiatives for networks of persons living with HIV and KPs to develop skills in policy analysis and advocacy 2. Disseminate Community – Led monitoring reports to national stakeholders 3. Advocacy and campaigning for HIV-specific issues 4. PLWH and KPs are facilitated to participate in national HIV events like WAD, Candle light day, Phily B Lutaya memorial 	CSOs, MoH, MoFPED, UAC Legislators, Parliamentary Committee of Health and HIV, Media

		(i.e. health unit management committee) community advisory boards)	<ul style="list-style-type: none"> 5. PWLH and KPs participate in Joint Annual Reviews for HIV and TB programs 6. Communities participate and present the assessment findings to various technical working groups at ministry of health and Uganda Aids Commission. 7. PLWH and KPs participate in national planning and budgeting processes 	
Regional		1. PLWH and KPs shape regional HIV/TB and SRHR policies and programs	<ul style="list-style-type: none"> 1. synthesis of evidence and lessons learned for regional engagements 2. PLWH networks and KP led CSOs participate in regional advocacy meetings to influence HIV/TB and SRHR programs 	East African community (EAC)
Global		1. Shape Global mobilisation efforts for HIV/TB and SRHR – global Fund, UNAIDS mechanisms, PEPFAR global planning processes	<ul style="list-style-type: none"> 1. Be expert witnesses during global HIV/TB and SRHR sessions bit by Global fund, PEPFAR or UNAIDS 2. synthesis of evidence and lessons learned for global engagements 	Donors UN Agencies like UNAIDS Global Fund

3.4 Community-Led Monitoring and Engagement M & E Framework

HIV is not just a health issue for it touches on all aspects of life—it is a social, cultural, political, economic, rights, health and development issue. The synergy between the HIV response and social development is crucial, and community responses to HIV encompass both issues. Community actions are fundamental to combatting stigma, discrimination and raising awareness of HIV and human rights, and for delivering programmes for prevention, treatment, care and support.

Area of focus	Outcomes	Means Verification	Assumptions
Health rights, responsibilities awareness	# Communities are knowledgeable of their health rights, responsibilities and obligations of health workers and duty bearers # Communities are aware of the minimum health care package for HIV/TB and SRHR related services	# Community surveys # Sensitisation reports # Community dialogue reports	Communities embrace rights awareness activities COVID19 will have subsided and allow for community engagement activities.
Surveys and Community Led Monitoring assessments by service users – HIV/TB/SRHR services	# Communities empowered to administer the survey tool # Communities regularly conduct community assessments of HIV/TB and SRHR services at health facilities.	# HIV/TB and SRHR Service Assessment Reports	Capacity of PLWH and KPs is built in data collection
Community Issues popularization and Dialogues	# Communities’ synthesis reports and generate findings from community assessments. # Service issues popularised in communities and demonstrate support towards the issues	# Community dialogue reports # Community sensitisation reports	Communities are enthusiastic to participate in community related activities

Health facility based dissemination and action planning	# Action plans drawn and implemented to improve HIV/TB and SRHR services # health facilities embrace findings and take action on issues highlighted.	# Health facility dissemination reports # Health Facility Action Plans	Facilities embrace the community led monitoring and engagement program
District level dissemination and engagement on key emerging issues from Community Led Monitoring	# districts make commitments on issues in community assessment reports # district plans and budgets integrate issues generated by PLWH and KPs # Securing accountability and fulfilling a watchdog role	# District dissemination reports # District Level Action Plans	Districts are willing to embrace engagements on HIV/TB and SRHR
Hold meetings with PEPFAR Implementing partners (IPMS) to share findings of CLM report and other PEPFAR TWG committees	# PEPFAR IPs integrate feedback of the assessments into their operational plans and budgets	# PEPFAR engagement reports # Peoples COP engagement report # Country Coordinating Mechanisms reports	# Resources availed in a timely manner
Conduct national dialogues on Community Led Monitoring Findings	# Findings of Community led monitoring reports integrated in national HIV/TB and SRHR plans and programmes # inclusion of community recommendations in national planning and funding, including Concept Notes to partners like Global Fund; COP # Securing accountability and fulfilling a watchdog role	# national dialogue reports # Country Coordinating Mechanisms reports	# Resources are available to facilitate participation of communities
Regional and Global engagements	# Global funding commitment towards proven and effective HIV/TB and SRHR intervention models.	# Global mechanisms participation reports # Resource commitments secured from various bodies	# Resources are available to facilitate communities to participate in global events

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5. **Message Guide for Community Engagement Facilitators** Engaging and Mobilizing Communities for Action on HIV Testing, PMTCT, ART (PEPFAR 2019)