UNAIDS | June 2023

Community-led Monitoring Guiding Principles

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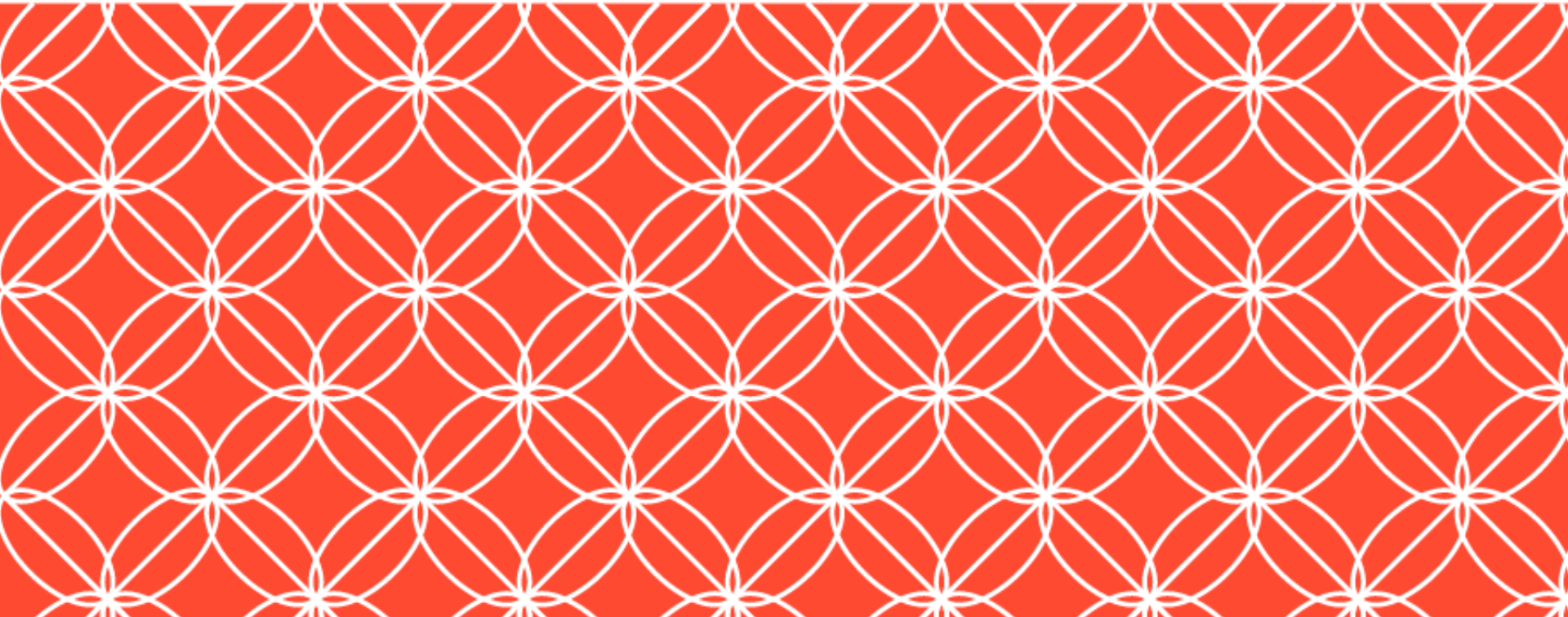
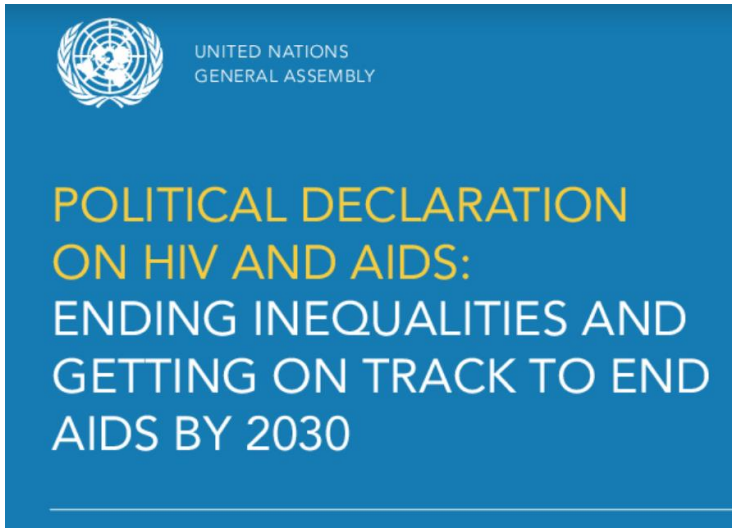


UN Member State Commitments in the 2021 Political Declaration on HIV and AIDS

By 2025, community-led organizations will deliver:



- **30 per cent of testing and treatment services,** with a focus on HIV testing, linkage to treatment, adherence and retention support, and treatment literacy;
- **80 per cent of HIV prevention services** for populations at high risk of HIV infection, including for women within those populations;
- **60 per cent of programmes to support the achievement of societal enablers** to dramatically reduce HIV-related stigma and discrimination, punitive laws, and gender-based violence.

Who are we referring to when we speak of Community

- ✓ Communities are diverse and dynamic, and one person may be part of more than one community. Communities are formed by people who are connected to each other in distinct and varied ways.
- ✓ People who health systems are trying to reach and whose health they aim to improve.
- ✓ People who are particularly affected by a given health problem.
- ✓ People who share specific characteristics or vulnerabilities, such as due to their gender, identity, geography, behaviour, ethnicity, religion, culture or age.
- ✓ Groups that represent these people.

Community-led Organisations

Location

A group of people with shared characteristics

NOT the same!!!

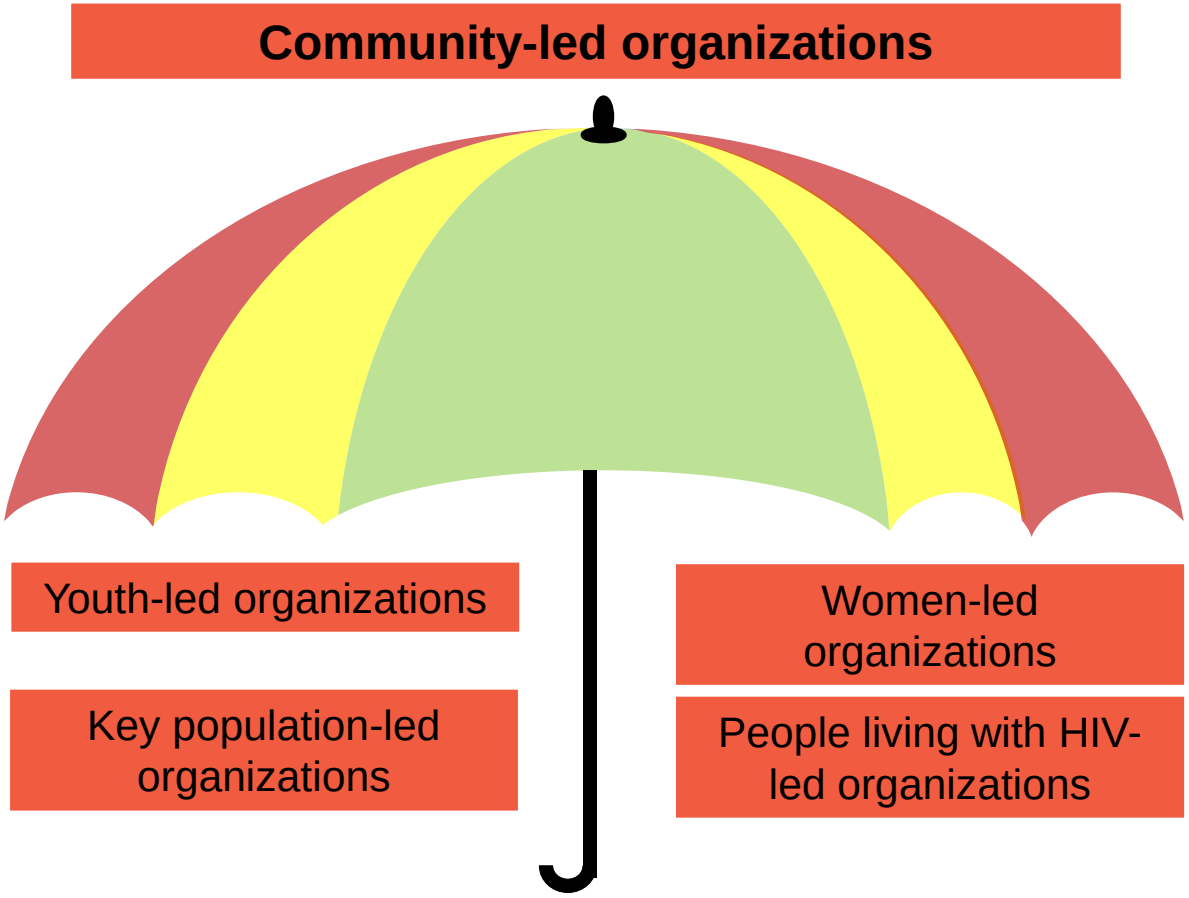
Community-based

Community-led

Community-led organizations, groups and networks, whether formally or informally organized, are entities:

- ✓ for which the majority of governance, leadership, staff, spokespeople, membership and volunteers, reflect the experiences, perspectives and voices of their constituencies and
- ✓ who have transparent mechanisms of accountability to their constituencies.
- ✓ Community-led organizations, groups and networks are self determining and autonomous. and not influenced by government commercial or donor agendas.
- ✓ Not all community-based organizations are community led.

CLO is an Umbrella Term, inclusive of all peer - led organizations



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Community-led Monitoring (CLM)

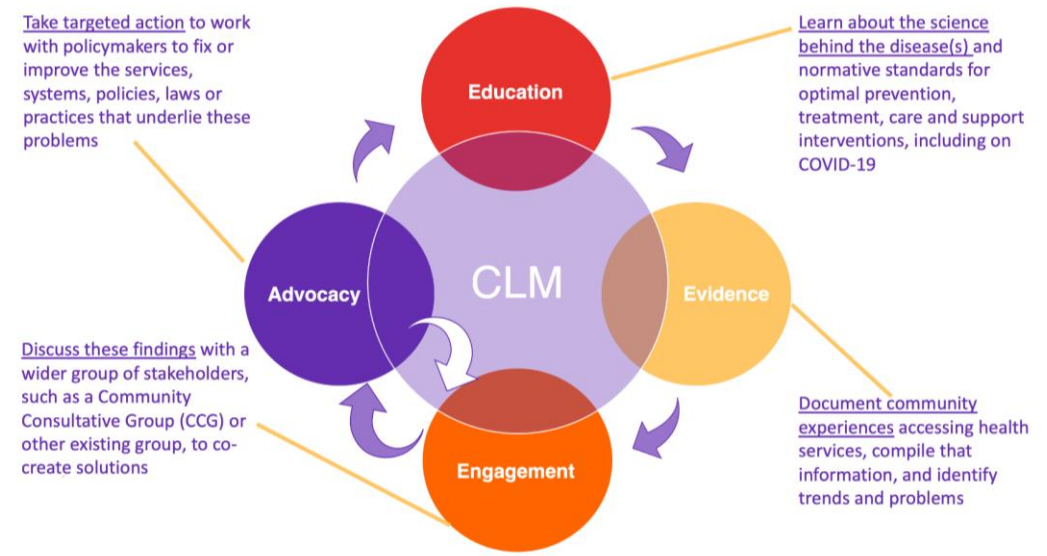
HIV Community-led Monitoring (CLM) is an accountability mechanism for national HIV responses, led and implemented by local community-led organizations of people living with HIV (PLHIV), networks of Key Populations (KPs), other affected groups, or other community entities.

- ✓ CLM uses a structured platform and rigorously trained peer monitors to systematically and routinely collect and analyze qualitative and quantitative data on HIV service delivery, including data from people in community settings who might not be accessing health care, and establish rapid feedback loops with program managers and health decision-makers.

- ✓ This data is used for monitoring trends along the HIV care cascade, and to inform targeted action that will improve the quality of HIV services

CLM Lifecycle

When problems uncovered through CLM aren't resolved, communities escalate with evidence-based advocacy and campaigning until they achieve implementation of corrective actions by duty bearers.



ITPC Community-Led Monitoring Model 2021

Essential Elements:

- **Led** by communities that are representative of people being served by services
- Focused on **action** and **accountability**
- **Independent**
- **Collaborative**
- Routine and **systematic**
- Transparent, with results being **used for action** and disseminated

Rationale & Examples

Why CLM?

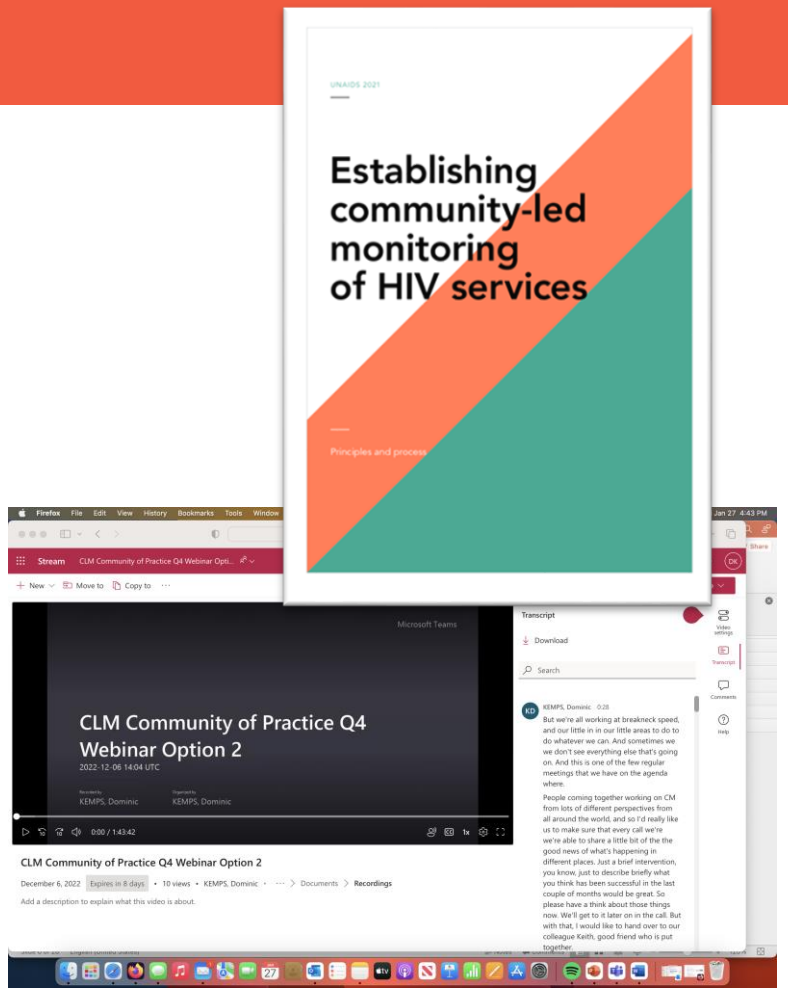
- **Process** (capacity of communities) and **Outcomes** (health or rights) focused
- Focus on improving **quality** of services/life
- **Optimising** investments (and validating Global AIDS Monitoring data)
- Raising awareness of **human rights** violations

Examples

- In Benin, REBAP+ identified that laboratory reagents had been out of stock for 10 months resulting in PLHIV not receiving viral load or CD4 tests. After REBAP+ advised the National AIDS Control Program, supplied was restarted
- In South Africa, 88% of PLHIV said that a health-care provider had explained the results of the viral load test results in 2022 up from 77% in 2021 – an indicator of health and risk of onwards transmission. The result was a 2% increase in the proportion of PLHIV who were aware of U=U
- In Kyrgyzstan, TB People conducts regular CLM of TB services including reporting on cases of human rights violations. As a result, the Ministry of Health created “trust councils” (public oversight boards with civil society representatives) at TB clinics that now use CLM data to improve services

UNAIDS support for Community-led Monitoring

- **Guidelines:** *Establishing community-led monitoring of HIV services*
- Support **Global CLM Community of Practice**
- **Tools** (eg. Progression Matrix)
- **Technical Assistance** through TSM
- Direct support to communities at country level to design, develop and deliver CLM
- Coordination with donors and other development partners



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Global CLM Review Meeting

Towards a Global Agenda for Community-led Monitoring

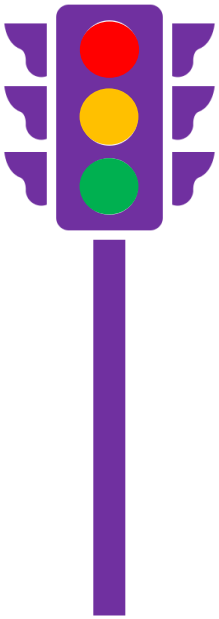
August 2022, Bangkok

- Identified several challenges in aligning CLM principles with practice
- Aligning CLM Principles to Practice
  - Community-led (from identifying what needs to be monitored and where, to leading the process of evidence generation and use)
  - Affected groups / communities (this includes PLHIV and key populations)
  - Quantitative and qualitative data (going beyond health facilities; treatment and prevention, human rights)
  - Accountability (at different levels; target the right duty bearers, fund advocacy)

Turning Principles into Practice – Key Questions?

- In many countries, CLM is being implemented in a manner that is out of step with the guidance set out by UNAIDS and other partners. What solutions can we propose to remedy this?
- How do we address challenging operating environments where it is hard to implement according to the core CLM principles?
- How do we support contexts where communities are partially, but not fully, leading to become in charge and independent?

A Methodology to track CLM progress over time



Off Matrix: Any single, multiple or even all variables do not yet meet Principles of CLM are in 'Red' and focus should be moving each variable currently 'off' matrix onto the matrix

Basic / Pilot: Implementation demonstrates some of the principles of CLM

Refinement & Insight: CLM implementation maturing with on-going adjustments (such as including new partners, refining data strategy) to improve impact

Systemisation: CLM model is showing impact and expanding with some evidence of CLM data/results informing health system delivery/performance enhancements

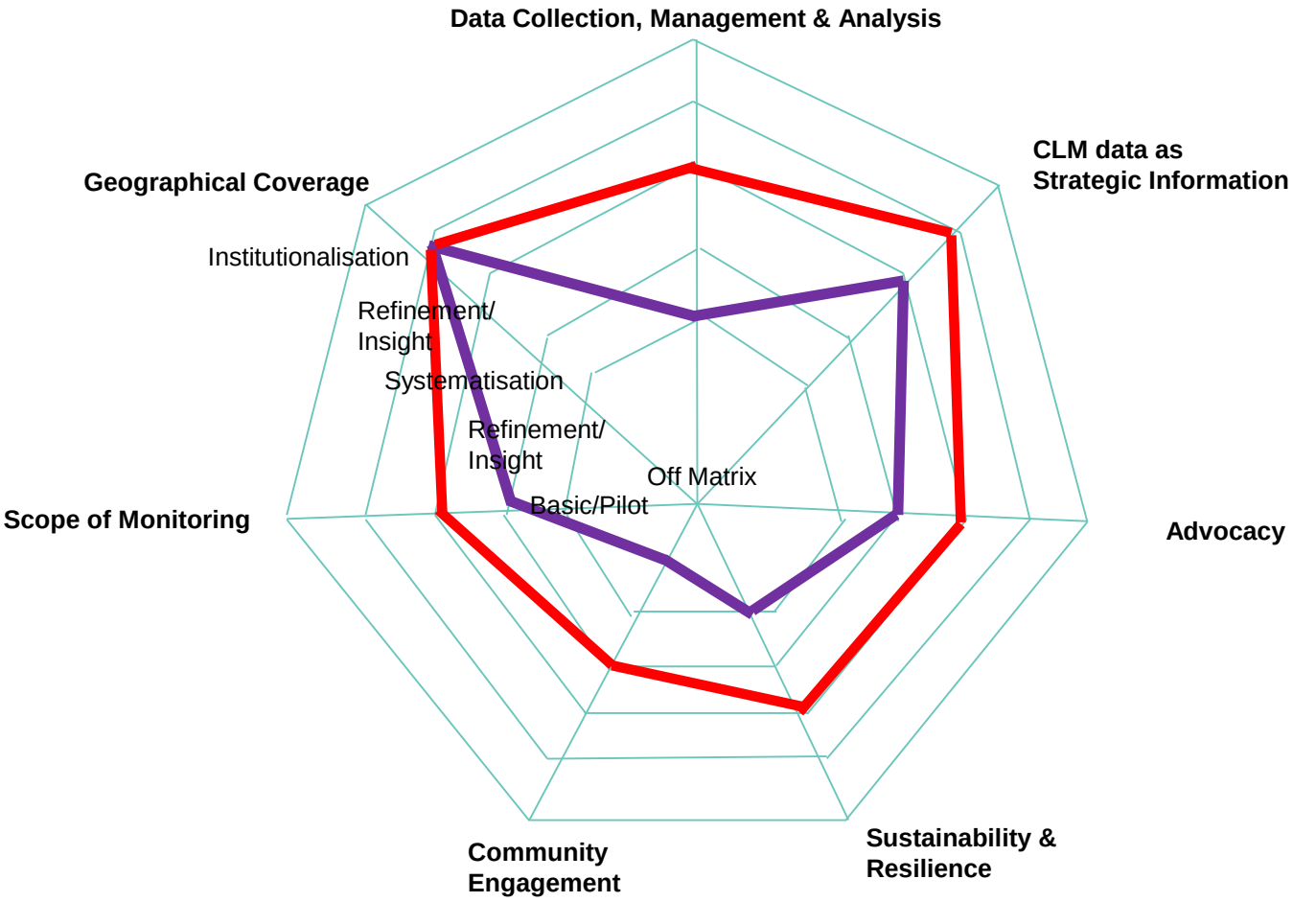
Consolidation: CLM is adopted as a key strategic programme but limited scope – either in terms of geography, funding available or populations covered

Institutionalisation: CLM is systematically embedded in country strategy for healthcare delivery with results informing continuous improvements and sustainable resourcing

Progression Matrix

	Off Matrix	Basic / Pilot	Refinement and Insight Stage	Systematization stage	Consolidation stage	Institutionalisation stage
Community Leadership	Not currently led by communities. CBM programmes or programmes that may only minimally involve PLHIV and KPs	Initiated by a PLHIV/KP network with support from donors/technical partners or by a CSO that is transitioning to include PLHIV/KP into a leading position.		PLHIV/KP network(s) leading CLM implementation with limited external technical support. They may be providing capacity support to new smaller CLM implementers in-country (or elsewhere)		Local PLHIV/KP network(s) act as hub for CLM with increasing numbers of Community CLM implementers year on year
Scope of Monitoring* **Note that the focus of this document is on those groups most affected by HIV and therefore emphasizes PLHIV and KP groups. Groups to be included will vary if applied for other health interventions*	Piecemeal, significantly time-limited, not focused on KP or PLHIV groups or a one-off	CLM of at least one type of HIV service or Rights issue (HIV treatment, HIV prevention or Human Rights) with priorities set by communities – but possibly not including all PLHIV and KP in design and implementation		CLM activities are comprehensively (or near comprehensively) monitoring HIV health and non-health service delivery for some but not all KP and PLHIV populations with priorities set by communities	CLM activities are comprehensively monitoring HIV health and non-health service delivery for PLHIV, KPs and other vulnerable groups with priorities set by communities	CLM supporting integration of HIV and other health services serving PLHIV, KP and other vulnerable groups with priorities set by communities
Geographical Coverage	Geography(ies), facility(ies), district(s) undefined and/or buy-in of local health services or communities not secured	Wherever CLM is implemented, it is adequately resourced At a minimum when resources for CLM are limited, they should be concentrated where they would have the most impact		Multiple geographic areas with prioritization based on transparent criteria of election based on service delivery performance, community priority or other priority identified by communities	All priority regions/provinces, urban and/or rural areas, covering all high and a significant proportion of moderate volume facilities seeing PLHIV, KP and vulnerable populations	
Data Collection, Management & Analysis	Not undertaken by PLHIV or KP populations or populations not trained to undertake CLM	Data collection tools are developed/adapted to the local context and used; data is confidential and safe. It is owned and managed by community implementers. May be project based; not continuous.	CLM data collection and analysis systems are setup for continuous use (dependent on funding available); data is confidential and safe. It is owned and managed by community implementers	Data is routinely collected (at least quarterly), safely stored, verified, analyzed and compared among regions and over time; data is quality assured and credible received by national stakeholders. Data collection tools are revised with input based on lessons learnt on previous data collection stage, including community feedback. CLM systems are recognized for their local community data collection value & insights which validate and complement national health/GAM data		CLM exists as a parallel data system to GAM **at community level.** There are systems in place that ensure that CLM data is timely, complete, clear, and coherent; analysis is undertaken and formal data supervision and quality assessments are regularly conducted and adjustments to tools are made when needed
CLM Data at Strategic Information	No feedback loop into health services to deliver service improvements	CLM is **grassroots based with** accountability primarily taking place at local and sub-national level by the communities themselves. CLM data collected is shared with all stakeholders to inform service improvement discussions		CLM is a **grassroots,** accountability/health system performance monitoring intervention implemented at local, sub-national and/or national level by community-led organisations CLM data are triangulated with those from national information systems for HIV services and CLM (where implemented) is considered an integral part of the national accountabiility mechanism for HIV and health programmes and used on on-going basis to inform service delivery improvements and/or hold health (or other) system accountable for deviations from policy or rights violations in order to improve national HIV response		
Advocacy	No advocacy plan in place or activities in practice	At least one meeting with the government (above-clinic level) has been organized where findings and recommendations have been developed based on CLM results	Meetings (above clinic-level) either ad-hoc or regularly to develop recommendations/ solutions based on CLM data and findings	CLM is systematized as part of a regular process of soliciting community feedback, based on the tracking of health system (or human rights) performance against commitments, and delivering that in a routine way to decision-makers through advocacy		There is a clearly documented cycle for CLM data to inform advocacy, and recognition that CLM has led to improvements of HIV services
Sustainability & Resilience	No funding in place, being implemented voluntarily with minimal or no capacity building support for communities	Resources and systems for a full CLM cycle are in place with community capacity to lead being supported within a geographic area (including remuneration for community workforce)		Fully resourced by one or more donors for longer than one full cycle, with established systems and skilled personnel who are informed by the community and which link to health facilities	Sustainably resourced, with established systems and skilled personnel who are building capacity of other communities to lead CLM	CLM activities where implemented are fully funded as routine expenditures (including domestic resources), with community expertise and capacity recognized and proactively informing other areas of health service delivery.

Using Progression Matrix



Application:

The matrix is a flexible tool that has been used for mapping, reflection and planning.

The fictitious example indicates in **purple** an assessment of CLM progress to date and the line in **red** indicates goals agreed by partners for coming year.

The Matrix encourages both honest assessment and forward looking goal-making to continuously improve CLM practice in-country.

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Thank You

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