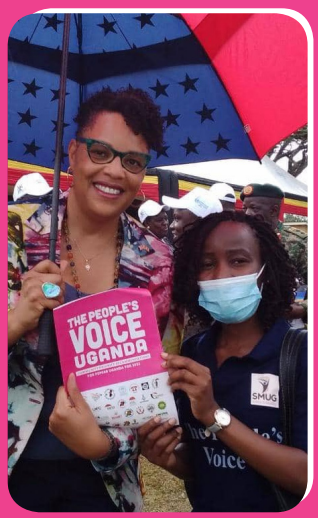
COMMUNITY LED MONITORING



Community Led Monitoring (CLM)

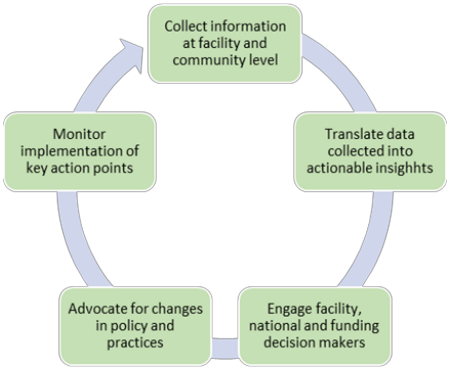
Community-led monitoring is a unique innovation for quality improvement approach that puts People living with and at high risk of HIV/TB and service end users at the forefront of influencing services (accessibility, availability, affordability, acceptability, quality) from their individual lived experiences.

This innovation helps programmes by:

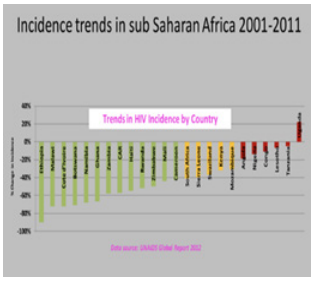
- Sharing of best practices and through cross learning;
- Generating evidence and using it to engage with policy/decision makers, programmers and implementers;
- Identifying gaps and challenges in policies, programmes, funding and implementation mechanisms;
- Demanding for increased investments and;
- Recommending innovative interventions

and approaches.

The Community Led Monitoring Cycle



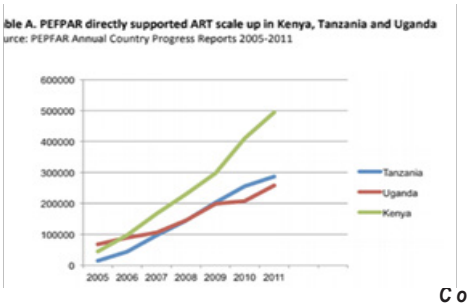
The Community Led Monitoring journey



Uganda HIV&AIDS indicator survey

The precursor to CLM in Uganda started as early as 2010, when Uganda was experiencing an increasing HIV incidence and the HIV prevalence showed a slight increase in HIV prevalence since the 2004-05 UHSBS, from 6.4% to 7.3% of adults age 15-49 [ ]. The trend did not impress the Networks of PLHIV, Vulnerable and Key Populations, CSOs & CBOs.

PEPFAR Annual Country Progress report



Under the leadership of International Community of women Living with HIV Eastern Africa (ICWEA), PLHIV & those at high risk of HIV/TB, CSOs, & CBOs with support from Global Allies [ ] set out on a fact-finding mission to ascertain the causes of this trend. The findings revealed that, PLHIV on treatment were having poor treatment outcomes as they were losing out on lifesaving treatment, and those newly diagnosed were not getting enrolled into care thus presenting with disease progression very quickly due to fear and stigma associated with HIV.

The findings further revealed that the country had insufficient ART to maintain those on care as well as initiate new clients on treatment and this was as a result of the ART Caps instituted because of the PEPFAR budget cuts from congress.

Forming itself into a coalition, the group developed a 10-point action plan for ending HIV&AIDS in Uganda focused on averting new infections, saving lives and ensuring leadership for the HIV response. The impact of CSO actions was making news in the New York times but also compelled Congress to reconsider the PEPFAR budget cuts. After 2010, the Community-CSO and PEPFAR Collaboration was re-born. The lessons picked from 2010 advocacy on ART Caps was that there was limited Community voice and from 2012, ICWEA sought a community engagement grant from AVAC to amplify the community voice.

Since 2012, the International Community of Women living with HIV Eastern Africa (ICWEA) has been coordinating, mobilising communities to engage and participate in PEPFAR program oversight and accountability meetings including SITEs, SIMS and POART meetings.

The CLM leadership and scope widened with the joining of Coalition for Health Promotion and Social Development (HEPS Uganda -representing mainstream CSOs) and Sexual Minorities Uganda (SMUG – representing KP CSOs). As such CLM involved the following;

- Networks of communities affected & impacted & CSOs meetings with PEPFAR; at the Embassy;
- Dialogues with the wider CSOs on to reflect and discuss PEPFAR data.
- PEPFAR agreed to structured meetings including inviting and supporting CSO participation at the Regional Planning Meetings (RPM).

In 2020, the CLM Consortium in Uganda received funding from PEPFAR (CDC) through UNAIDS to implement CLM. The PEPFAR CLM award enhanced and strengthened Community Led social Accountability in the areas of data systems, community empowerment and advocacy, community leadership and coordination, and monitoring of changes impacting HIV/TB service delivery.

[1] AIDS Indicator Survey (AIS), 2010
[2] Global Health Access Project (Health Gap)

Objectives of CLM Overall objective:

To improve the quality, availability, accessibility, affordability, acceptability and utilization of HIV and TB services in Uganda.

Specific Objectives:

1. To strengthen systems and capacity of communities to collect, analyse, interpret, and disseminate CLM data; use CLM data to advocate for improvement in HIV service delivery and monitor implementation of agreed action points;
2. To generate and make evidence available (from the service recipient perspectives) on availability, accessibility, affordability, acceptability, quality, awareness, and appropriateness of HIV/TB services;
3. To use evidence to advocate for delivery of uninterrupted quality and comprehensive HIV and TB services with the intention to improve performance;
4. To strengthen programme management (oversight and accountability), for effective and efficient delivery of better health outcomes.

Why Community Led Monitoring?

In 2020, the Uganda population HIV Impact Assessment (UPHIA), HIV prevalence in Uganda is 6.2%, having declined from 7.3% in 2010. Despite this progress, the PEPFAR program was also indicating significant challenges with case identification for men, Challenges with two-month testing coverage among HIV Exposed Infants (HEI), treatment losses due to clients falling off the treatment cascade and poor viral suppression results (As of December 2019, 78% of HIV-infected men aged 20 years and above had been diagnosed, 76% of them were on treatment and 59% had attained viral suppression.)[1]

While several complementary national M&E plans addressing HIV service delivery quality have been implemented, like the Ministry of Health's National Quality Improvement Collaborative and PEPFAR's "Surge for Quality", these plans have not focused on assessments of the accessibility, availability, affordability, Acceptability and quality of HIV/TB service delivery from the perspective of the clients themselves Sustaining CLM as a program and using the evidence from this program is pivotal in closing the critical gap in the accountability of the HIV response to the clients served by PEPFAR in Uganda.
Service beneficiaries have the greatest stake in improving treatment and prevention program quality and accessibility and are often the first to detect problems, diagnose causes and take on risks as they sound the alarm.

Therefore, the CLM approach would help PEPFAR in fixing program quality gaps when it collaborates with independent Civil society organisations.

[1] COP20 Strategic Direction Summary

How Community Led Monitoring works

CLM implementation is guided by a set of principles and these include;

The Cardinal principle of CLM is that it is led and driven by communities living with and affected by HIV&TB.

The Independent civil society and community-based organisations that make up CLM Uganda is inclusive of: Networks of People Living with HIV; Key population networks; Networks of young people living with HIV; Networks of women living with HIV; and People living with disabilities.

Selected members of the community who are directly impacted (community monitors) engage other service recipients to identify barriers (gaps and challenges), and enablers (best practices) in HIV/TB service delivery programs. These are electronically documented through the electronic data collection system for analysis and display on a Public Data Dashboard. The evidence generated is an opportunity for communities to engage with policy, decision makers and programmers; to hold duty bearers accountable through the engagement framework.

[1] Community led is defined as: "Self-determining and autonomous organizations whose governance, leadership, staff, spokespeople, membership, and volunteers represent the experiences, perspectives, and voices of their constituencies, who have transparent accountability mechanisms to their constituencies, and who are not influenced by government, commercial, or donor agendas

CLM coordination and implementation structure

Oversight: The Advisory committee of 11 Constituency members oversees and provides oversight to the CLM program including Overseeing that all interventions under the project are in line with the project support documents

- Monitor implementation of the project and ensure that strategic changes are undertaken in a timely manner so that the project achieves its goals.

- Provide policy guidance to the implementing team Participate in promoting policy dialogue and advocacy on issues identified by the project at National Level. Prepare and submit quarterly reports on constituency engagement to the implementing team.

The 11 Constituencies comprising the steering committee include: Women living with HIV, young people living with HIV, PWDs, Religious Leaders, Men living with HIV, KPs (FSWs, MSMs and PWIDs) and PLHIV Network

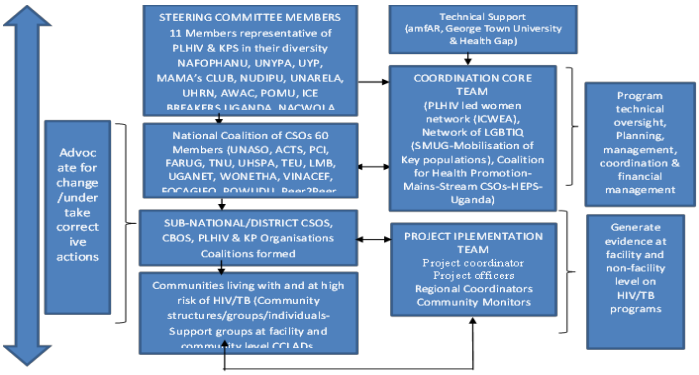
Implementation

CLM implementation is led by a consortium of three; two community led organisations-ICWEA and SMUG and one Civil Society Organisation (CSOs) . The Consortium has a team of project officers, field teams including Regional Coordinators and Community Monitors.

Advocacy and engagement

The structure engages communities through a National CSO Coalition on PEPFAR Engagement processes and District and regional coalitions for PLHIV and Key populations respectively.

Figure 1: CLM Coordination and Implementation Structure



How we engage