CSS Walked so CLM Could Run: Examining Community Led Monitoring for Improved HIV Service Delivery

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BACKGROUND

In 2021 the United Nations declared to end disparities towards AIDS elimination in 2030 through the establishment of 2025 targets. The declaration re-affirmed the need to address and combat the factors that continue to promote unbalanced progress such as 2020 estimates of six in every 10 new infections occurring in East and Southern Africa and only 43% of People living with HIV (PLHIV) in in the Middle East and North African region having accessed Antiretroviral therapy (ART).

In addition to regional disparities, population differences in HIV control persist, for example in 2020 "key populations" and their partners accounted for more than 65% of new HIV infections. Additionally, one in three countries reporting that at least 10% of their key populations avoiding health care services due to discriminatory attitudes or harmful laws.

The need for accountability to drive improved service delivery

There is growing recognition that social accountability gaps at the state-society interface are a key driver of poor provision of public services and that has driven new approaches in health, development, and political science, focused on creating accountability between the triad of communities, political leaders, and the "street-level bureaucrats" responsible for local public services. In the HIV political ecosystem, decision-makers that fund HIV programs are rarely also users of the HIV services over which they exercise control. To add to the complexity, aid funding directly supports public services—creating a further democratic deficit as aid decision-makers are outside traditional lines of accountability between citizens and their governments.

There is an increasing emphasis in global health, and in particular in the HIV, TB, and Malaria response efforts, on expanding community-led responses (CLR), with a recent study showing that community leadership within the HIV response resulted in "comparative advantages" across several priority areas towards improvement of outcomes including improved retention in care, increased viral load suppression and awareness of human rights as well as a reduction of treatment stockouts.

METHODS

Community Led Monitoring (CLM) is a CLR approach to overcome disparities in access to quality HIV testing, treatment and prevention using community-owned solutions to poor quality service delivery encountered and documented at the health facility level. It builds upon Community Systems Strengthening (CSS) efforts to structure and strengthen community-level health interventions. Though different, the relationship between CLM and CSS has not been clearly explained in the literature.

We examined both approaches by conducting a literature review and informational interviews with program experts involved in community response and systems programs.

We then composed case-studies of three CLM Projects in Uganda, South Africa, and Haiti to examine operational country-specific CLM projects. Using these materials, we qualitatively analyzed CSS and CLM components and phases into service improvement, capacity building, and accountability & policy change.

The aim of this work was to differentiate the two approaches and define CLM as a distinct accountability structure for improving HIV services.

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COMMUNITY SYSTEMS STRENGTHENING

The 2010 Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) Community Systems Strengthening Framework was one of the earliest documented efforts to formalize community participation in the HIV response. The HIV movement for affordable and accessible treatment was driven by organic community activism and mobilization, which expanded the civil space for community organization and programming for health. As an early GFATM partnership model this framework initiated the funding stream toward community-level interventions.

The community systems concept, according to the CSS Framework, aimed to list the technical and financial elements needed to create a community level structure for mobilizing populations affected by HIV, TB, and Malaria. [Figure 1]

The framework offered "core components" which includes advocacy, coordination, capacity building, service delivery, organizational strengthening and monitoring and evaluation and planning [FIGURE 1]. They were analogous to health system strengthening building blocks and linked to the shared outcomes towards Global HIV impact. For example, CSS projects focused on extending the reach of primary health care services by aligning the activities of health professionals with community-based organizations such as community health workers (CHWs). For example, CSS efforts would focus on positioning nurses at clinics to train and coordinate CHWs in order to increase the number of of people referred and visiting the nearest health facility for medical attention for various ailments.

CONCLUSION

While both CSS and CLM support capacity building of Community-based Organizations to drive improved health service delivery, CSS, the earlier intervention focused on formalizing community-level interventions within the health system in order to extend and optimize health service. CLM builds on these established systems **and** catalyzes community ownership of health services as an effective intervention for improving both quality, social accountability, and policy change as a part of the community-led HIV response.

Figure 2. CLM Phase Cycle

COMMUNITY LED MONITORING

Community-led monitoring, is the routine observation of the quality and accessibility of health services by members of directly affected communities and advocacy focused on decision-makers to address problems revealed by observation. A key requisite of CLM is that it must be owned and led by organized communities, specially by those who regularly use the services monitored. The monitoring is based on quantitative and qualitative data collection and analysis that reveal insights from communities about the problems and solutions to health service quality issues at the facility, community, sub-national, national, and even international levels. Organised, independent groups led by affected people house the monitoring activities--training, supporting, equipping, and paying them.

CLM, includes the full integration of evidence-based advocacy into a cycle that brings new information to the attention of decision makers and acts to hold them accountable for acting on that information—an element that separates it from other modes of quality improvement or transparency. Data collected by communities informs CLM advocacy goals and measures implementation of agreed solutions, for example via a set of evidence-based advocacy recommendations that form the basis of donor-facing accountability efforts, as with The Peoples Country Operational Plans (known as the Peoples COP) a parallel advocacy document developed by communities to shape PEPFAR's COPs. [Figure 1]

The CLM five-stage implementation cycle is characterized by data collection, translation, dissemination, advocacy, and monitoring. Unlike research, it is focused on a goal of improving service quality rather than generating generalizable knowledge. [Figure 2]

Figure 1. CLM overall program structures with country case study examples

Community-Led Monitoring

	Service Improvement	Capacity Building	Accountability & Policy Change
CLM Implementation Phases	PHASE 3 Bring information to the attention of decision-makers	PHASE 1 Collect information at facility & community level PHASE 2 Translate data collected into actionable insights	PHASE 4 Advocacy for changes in practice & policy (including creating venues for engagement with political leaders) PHASE 5 Monitor implementation of promised changes
CSS Core Components	CC4 Community activities and service delivery CC6 Monitoring and evaluation and planning	CC1 Enabling environments and advocacy CC2 Community networks, linkages, parntership and coordination CC3 Resources and capacity building CC5 Organizational and leadership strengthening	
CLM Implementing Country Case Studies	**CLM South Africa (Ritshidze)** •Ritshidze monitoring takes place at 400 clinics and community healthcare centers across 27 districts in 8 provinces in South Africa. Facilities chosen cover nearly half of all PLHIV on treatment in the country, with a focus on sites with large treatment cohorts and where data shows poor linkage and retention rates. •Ritshidze uses multiple quantitative and qualitative tools to collect data through observations and interviews with patients, PLHIV, key populations, Facility Managers, and pharmacists. •Data collected is used to assess key indicators around the quality of healthcare such as staffing, waiting times, clinic conditions, HIV and TB prevention and treatment services, and services for key populations.	**CLM Haiti** •L'Observatoire Communautaire des Services VIH (OCSEVIH) was launched in December 2020 established under the leadership of the Civil Society Forum and in partnership with UNAIDS and Housing Works. •Today, there are 12 Community Monitors trained on Commcare– the digital data collection platform. The CLM project covers 65 healthcare facilities across three departments (iNord, Ouest, and Artibonite), reaching 16 arrondissements.	**CLM Uganda** •Over the past year of implementation, the Project Team have convened several meetings with the StC, PHLIV and KVP communities, major funders of HIV/AIDS in Uganda, and government agencies, namely the MOH, to advocate for improvements in HIV/AIDS service delivery in Uganda. •This includes direct engagement with the PEPFAR Oversight Accountability Response Team and PEPFAR Implementation Partners.