

Community-Led Monitoring Drives Tailored Solutions and Improves Focus on Client-Centered Services

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Four components of the EpiC CLM system

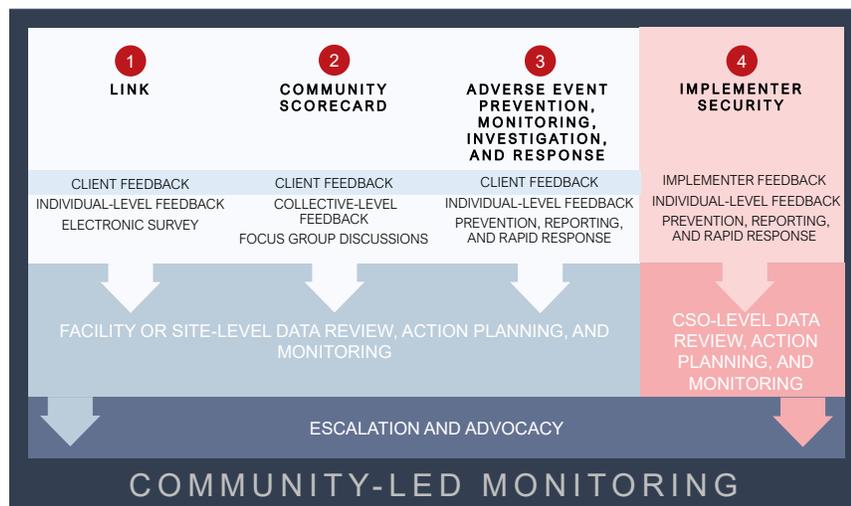
- LINK:** This component collects individual feedback and reports from clients accessing HIV services through brief surveys that measure satisfaction with HIV services, key factors affecting satisfaction, and open-ended feedback, which may include adverse event reporting. Because of frequent monitoring, issues reported through LINK can receive a quick response and ongoing attention.
- Community scorecard (CSC):** This component gathers collective input and recommendations from clients of HIV services through group discussions. The group discussions allow for in-depth exploration of issues and solutions. CSCs are complemented by key informant interviews with service providers and local health administrators that allow further exploration of service issues.
- Adverse event prevention, monitoring, investigation, and response (AEPMIR):** This component collects individual reports of adverse events and incidents of violence from clients accessing HIV services. To reinforce this reporting system, trainings are included for service providers on how to prevent adverse events, create an environment where clients feel comfortable reporting adverse events, and respond to adverse events when they are reported.
- Implementer security:** This component collects individual reports of adverse events and violence from staff at facilities or sites, including clinical implementing partners and service providers, to monitor their security. They may themselves be PLHIV or members of a key population or priority population. This reporting system is complemented by tools and trainings to help providers and implementers improve their security.

Client-centered health services require an understanding of service user perspectives—their priorities, experiences, and challenges. To this end, collecting and analyzing data from service users, particularly stigmatized groups such as people living with HIV (PLHIV) and key populations, are essential. Community-led monitoring (CLM) is overseen by community-based organizations and invites communities of people living with and affected by HIV to give feedback on the services they receive and use that data to improve their health, promote an enabling environment, and hold decision-makers and service providers accountable.¹

Although CLM is not new, there is increasing recognition among donors, including the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), of the importance of CLM to ensure health services are tailored to users’ needs and preferences.

The Meeting Targets and Maintaining Epidemic Control (EpiC) project, funded by the United States Agency for International Development (USAID) and PEPFAR and led by FHI 360, empowers local communities to monitor and improve the quality of HIV services through a CLM system with four components—group discussions, individual client feedback surveys, adverse event monitoring, and reporting on security issues experienced by HIV program implementers (Figure 1). The components complement each other to provide a comprehensive view of the HIV service experience. **This brief provides case examples documenting how the CLM system was implemented in Malawi and Nepal, how it empowered the clients of HIV services to identify pertinent issues affecting their care and suggest improvements, and how it ensured client-centered improvements were made.**

Figure 1. EpiC comprehensive CLM system



¹ Joint United Nations Programme on HIV/AIDS. Establishing community-led monitoring of HIV services. UNAIDS. 2021. Available from: https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf

CLM-driven feedback and advocacy from female sex workers (FSWs) lead to shorter wait times for antiretroviral therapy (ART) services and client-centered gender-based violence (GBV) services in Malawi

The EpiC Malawi program has been implementing the LINK individual-level feedback survey since 2017. LINK surveys are administered in person on tablets by peers, including members of key population groups or outreach workers whom the clients trust, with clients who are leaving the facility after receiving services. Suggestion boxes for adverse event prevention, monitoring, investigation, and response (AEPMIR), where clients can anonymously submit brief written reports of adverse events or general comments and suggestions for service improvements, have been available in health facilities since 2016. The program became aware of issues clients were facing when accessing services through data from the LINK surveys and comments from the AEPMIR suggestion boxes. When asked about areas in need of improvement, clients across districts frequently raised concerns about long waiting times at facilities. Comments received via the LINK surveys included:

“I waited for too long and nearly turned back. I spent four hours to access the services.”

“Waiting time is too long, and staff don’t pay attention to clients. They prioritize personal things other than clients.”

“I wasn’t helped on time. Staff were doing personal things and would pass by me frequently without even asking why I was on the waiting bench for so long.”

“Took too long.”

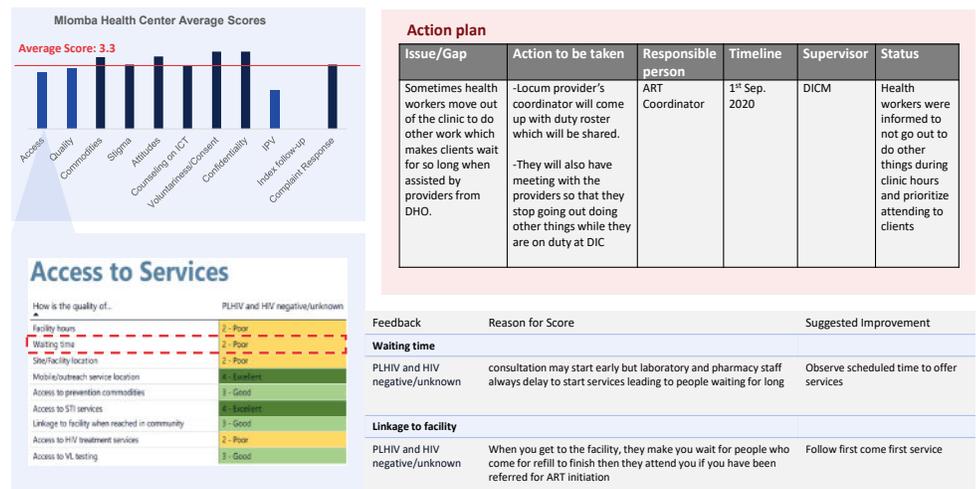
“Improve on time to start working.”

When the EpiC Malawi team began preparing to implement the community scorecard (CSC) component of CLM, they decided to include a question on this issue. They wanted to triangulate data between responses from LINK, AEPMIR, and CSC on the perception of wait times to better understand the clients’ experiences and gather their suggestions for improvements. The scorecard was adapted to ask, “How convenient are the waiting times of HIV testing and counselling and HIV treatment services?”

In August 2020, staff at two of EpiC’s local implementing partners conducted CSC group discussions in Lilongwe, Machinga, and Zomba districts with members of key population groups (FSWs, men who have sex with men, and transgender individuals) receiving services from seven health facilities and sites to assign scores to services provided by each site. Eleven technical areas of service provision were assessed for each health facility. To determine the quality of each technical area, clients answered questions relevant to that area and assigned a score of one (very poor), two (poor), three (good), or four (excellent). Zero, or not applicable, was an option when participants had not used the service discussed. The average score of the questions was used to determine the score for each technical area. After the group discussions, client representatives were selected to participate in an action planning meeting with stakeholders, including the health facility and district health office (DHO) staff, to present the issues discussed.

Figure 2 shows the findings of the CSC for the Mlomba Health Center, a government health facility in Machinga. The average score of the eleven technical areas was 3.3, and three of the technical areas, including access to services, scored below that average. The group discussion included nine questions on access to services, and the score breakdown showed four questions received a ‘poor’ rating, one of which was waiting time.

Figure 2. Community scorecard and action plan for Mlomba Health Center



Group discussions from each of the three districts validated the concerns raised via LINK and provided the opportunity to do a deeper dive into the issues affecting client-centered service delivery. It became clear the reporting of long wait times was not consistent across facilities. For example, in one drop-in center in Lilongwe, a focus group among transgender individuals scored wait time as “good,” but they commented, “It is mostly not long but at times take a long time to counsel one person.” They suggested having two counselors to speed up the process. Mlomba Health Center received a “poor” score during a group discussion among FSWs because “[the] consultation may start early but laboratory and pharmacy staff always delay to start services, leading to people waiting for long.” Additionally, in response to a question concerning linkage to facilities and sites after being reached in the community, a client said, “When you get to the facility, they make you wait for people who come for refill to finish, then they attend you if you have been referred for ART initiation.” They suggested the health facility change its services to be first-come, first-served (Figure 2).

Group discussion participants selected representatives from among themselves, as well as peers who were not in the discussions but could best represent them, to attend the action planning meetings. The FSW representatives and staff of the health facility, DHO, and CSO attended the Mlomba Health Center action planning meeting. The CSO staff summarized the main issues identified through the group discussions and the explanations for the scores, after which, the FSW representatives elaborated and provided suggested improvements. Action items included developing a roster to clarify responsibilities so that providers do not pause services for other work and making sure new and returning ART clients are seen on a first-come, first-served basis. The ART coordinator was assigned responsibility for completing these action items. Other action items were assigned to other relevant personnel in attendance, including the clients themselves.

Another issue the FSW representatives addressed was the lack of screening for intimate partner violence (IPV) during index testing. IPV services received the lowest score during the CSC discussions (Figure 2). When FSWs were asked whether they were screened for violence or abuse and about any harm committed by the partners named for index testing, the group members said this was not done and providers should start asking these questions. As a result of the FSWs raising this issue, the joint action planning group agreed on the need for further provider training on gender-based violence (GBV) and IPV screening, after which the refresher orientations were provided.

Box 1: Setting up the GBV monitoring and response system

Between April and September 2020, as part of AEPMIR, EpiC Malawi identified and trained crisis response teams, outreach workers, peer educators and navigators, and health facility staff on how to identify and appropriately respond to IPV and other adverse events to provide clients with opportunities for disclosure and encourage clients to report experiences of harm.

Quality of GBV services also surfaced during the CSC group discussions among FSWs receiving services from the Matawale Health Center in Zomba. During the group discussions, one member commented, “[The health facility staff] serve you only when you have brought police report no matter how serious you may be (even if you are oozing blood).” Additionally, a comment through the LINK survey said “Improve on treating GBV victims first, then police documents later.”

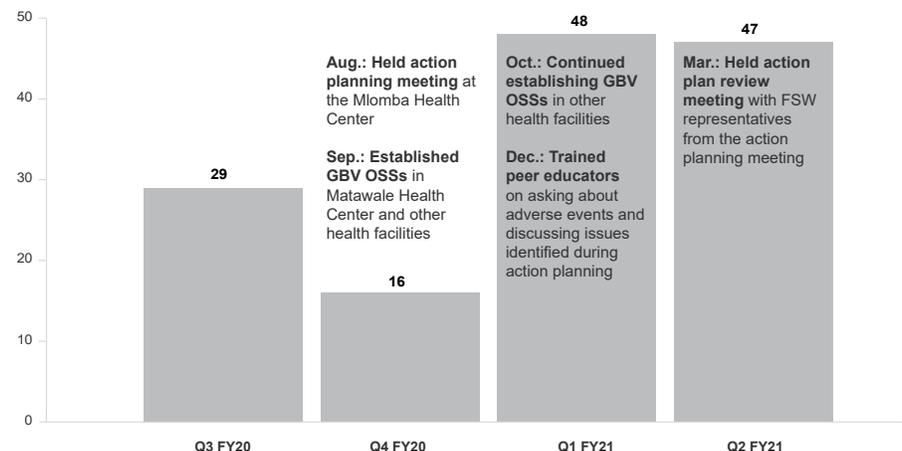
Figure 3. Scores assigned to the questions on access to services at Matawale Health Center

How is the quality of...	PLHIV and HIV negative/unknown
Facility hours	3 - Good
Waiting time	3 - Good
Site/Facility location	2 - Poor
Mobile/outreach service location	0 - Not Applicable
Access to HIV services	4 - Excellent
Access to prevention commodities	1 - Very Poor
Access to STI services	4 - Excellent
Access to violence response services	3 - Good
Linkage to facility when reached in community	4 - Excellent
Access to HIV treatment services	4 - Excellent
Access to VL testing	4 - Excellent

While the focus group participants assigned a score of 3 (good) (Figure 3) for “access to violence response services,” FSW representatives said these high scores were assigned because services are good when there is a police report. However, services are not accessible without the police report, and this prompted the FSWs to raise the issue during the action planning meeting. This led to a conversation about national health guidance, which calls for all health facilities to have a one-stop shop (OSS), where police, social welfare workers, and health care providers are available to support clients who have experienced GBV. At the OSS, they can file a police report and receive social support and health services. Because this was not in place, the Matawale Health Center staff were assigned to set up an OSS, and the DHO representative took steps to ensure all facilities in Zomba and Machinga implemented this service in line with national guidance and all FSWs were able to receive services with or without filing a police report. The inclusion of the FSW community in the process of identifying, prioritizing, and presenting the issues to key decision-makers was critical to making this needed change.

During the follow-up meeting at the Matawale Health Center, FSW clients said the OSS GBV services had been helpful and made it easier for them to receive necessary social and health services in a timely manner. While the AEPMIR system had responded to reports of GBV, the response now includes greater collaboration between the police, social welfare, the DHO, and the GBV crisis response teams, which were set up as part of the AEPMIR system (Box 1). The system has received more reports of violence as FSWs are able to report and seek support without fear and interference (Figure 4).

Figure 4. Number of individuals who disclosed to program staff or outreach workers outside of clinical facilities that they experienced violence within the past three months from any type of perpetrator in Zomba (GBV_REPORT_COMM [D])



Box 2: Ensuring safety of service providers through implementer security

Implementer security works in parallel with the other CLM components. Unlike the others, it is focused on prevention, monitoring, and response to adverse events and harm experienced by service providers and other implementers, who may themselves be PLHIV or members of the community.

Naulo Ghumti Nepal has a system in place that allows service providers to share their daily outreach activities, including index testing activities, in case of security incidents. The staff are taught how to immediately report incidents to the project coordinator so that quick action can be taken. In fall 2020, Naulo Ghumti Nepal assessed the security needs of their work environment and developed an action plan to improve its security. The team is now coordinating with the government to ensure the safety of service providers in the context of COVID-19. Monitoring and improving the security of implementers contributes to their ability to provide safe and ethical care to their clients.

PLHIV in Nepal provide perspective on index testing counseling and successfully advocate for specific changes and re-orientation of index testing providers

Index testing is an effective and efficient strategy for identifying PLHIV and linking them to care and treatment. In the EpiC Nepal program, only 5.4 percent (918/16,883) of all clients tested for HIV were reached through index testing, but HIV case finding from index testing accounted for 18 percent (228/1,267) of people who tested positive during the first two quarters of fiscal year 2021 (October 2020–March 2021). As with all HIV testing strategies, index testing must follow the 5Cs guidelines set by the World Health Organization (consent, confidentiality, counseling, correct results, and connection) to ensure clients' rights are respected, they feel comfortable, and they are prepared to be connected to further care.

HIV programming comes with some risks to providers as well, and index testing is no different. Ensuring the security of service providers—the physical security of the buildings and the security of outreach staff when working in the community—lays the foundation for high-quality services (Box 2).

To ensure this strategy was implemented in a safe and ethical manner, EpiC Nepal oriented providers on adverse event monitoring, investigation, and response and on identifying and responding to IPV in the context of index testing. The AEPMIR system provides clients a way to report adverse events, including those related to index testing, and CSC and LINK help to monitor the safe and ethical provision of index testing.

While no index testing-related complaints were submitted via LINK for the local implementing partner, Naulo Ghumti Nepal drop-in center, and feedback around index testing collected through the CSC was positive, suggestions and comments were made about the counseling provided. When asked how well the counselors explained index testing, PLHIV clients said during the CSC group discussions:

“Understood basic meaning, but not the exact details.”

“Counselors shared with us (information) but difficult to remember such technical points.”

“We cannot remember such details but understand that it is to protect us.”

When asked how voluntary they felt index testing was, a PLHIV client said:

“Right to say ‘no’ is shared, but still feels pressured to disclose.”

PLHIV client representatives presented this feedback during the action planning meeting with health facility staff and CSO staff, and action points were assigned to health facility staff to provide further orientation and regular retraining of the counselors on index testing. The staff members integrated the follow-up on the action items and the refresher on the 5Cs of index testing for all community and clinical staff into their weekly team meetings. The refresher index testing trainings focused on gaps identified by PLHIV clients. In their feedback, PLHIV clients indicated the regular refresher trainings on index testing, conducted under AEPMIR, should be focused on specific components most in need of improvement. The health facility has not received complaints regarding index testing since the implementation of the action items. By asking clients for specific suggestions for service improvement, even services that may not be highlighted as problem areas can be improved and tailored to the clients' needs.

Providers will continue to receive ongoing supportive supervision in index testing as well as regular refresher trainings. Future coaching and training will focus on areas identified through LINK and the AEPMIR system.

Conclusion

EpiC's CLM has now been implemented across seven countries where services continue to be monitored and improved. The technical guidance for EpiC's CLM is available to be adapted and used by HIV programs everywhere to identify improvement needs, apply client-centered solutions, and set up monitoring and response systems to appropriately respond to incidents of harm or adverse events experienced by clients and service providers in a timely manner.

EpiC's community-led monitoring resources are available here: <https://www.fhi360.org/resource/community-led-monitoring-resources>.

For all other inquiries, please contact  Hally Mahler, EpiC Project Director: hmahler@fhi360.org

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