UNAIDS 2021

Frequently asked questions

Community-led monitoring

Question 1: What is community-led monitoring?

Answer: HIV community-led monitoring (CLM) is an accountability mechanism for the improvement of service quality and access. CLM is led and implemented by local community-led organizations of people living with HIV, networks of key populations and other affected groups.

CLM uses a structured platform and rigorously trained peer monitors to systematically and routinely collect and analyse qualitative and quantitative data on HIV service delivery. It uses these data to establish rapid feedback loops with programme managers and health decision-makers. This includes data collection from people in community settings who might not be accessing health care.

CLM compiles evidence on what works well, what is not working, and what needs to be improved, and provides suggestions for targeted action to improve outcomes. Through CLM, communities work together with service providers and decision-makers to propose solutions to access barriers and other issues that reduce the quality of services. CLM can then monitor whether the commitments made to address these problems are implemented and do improve the service quality. In this way CLM helps in holding decision-makers accountable.

In short, CLM is both owned and conducted by the community, and it contributes to the improvement of services that benefit the community. CLM is an element of the community-led response to HIV and AIDS, and it provides an opportunity for community networks and groups to play their watchdog function. CLM priorities should be decided through community consultation, free from influence from entities and agendas external to communities.

Question 2: What is not community-led monitoring?

Answer: Community-led organizations are frequently HIV service providers. Routine reporting and monitoring of their own service provision is not CLM. However a CLM coalition team can monitor community-led service provision when any conflict of interest is well managed.

Community data collection and analysis that are not carried out by community-led groups—or that are conducted against their will, under the influence of entities that are external to community-led networks and groups—are not considered to be CLM.

In some settings, particularly where key population groups are criminalized, the legal and policy environments are not conducive to community-led groups conducting CLM. It is accepted that other community groups and civil society organizations that are trusted and invited by the stigmatized population can receive funds, and organize and conduct CLM in collaboration with the key populations. Such outsourcing is not ideal, but if it is unavoidable, it should always be associated with capacity-building in the affected population, and it should contain actions to mitigate and challenge the unfavourable

policy environment. Even in those instances, however, CLM data collection should be performed by local community groups.

One-off, ad-hoc community-led data collection exercises or research that is not repeated on a regular interval are not examples of CLM.

Question 3: Is community-led monitoring totally different from Treatment Observatories?

Answer: There are many similarities between CLM and Treatment Observatories. CLM covers a broader range of topics than Treatment Observatories, while the latter follows all of the principles of CLM. The current Treatment Observatories conducted in countries are already covering the client monitoring of stigma and discrimination, medicine and test kit availability, and user fees. CLM, however, could also cover other services provided in community settings, such as prevention efforts. The methodologies and key questions related to CLM for prevention services maybe different from those for treatment-related services: the knowledge base around this will improve as countries and partners gain experience.

Question 4: Is community-led monitoring a duplication of monitoring and evaluation?

Answer: CLM is not a duplication of government-led HIV programme monitoring and evaluation (M&E) systems.[1] Rather, it is complementary to those systems. HIV M&E as a national or local effort—or for specific programmes—follows a standardized set of indicators to report on progress and service quality against set targets, usually collected on a routine basis by the implementers. CLM, however, provides unique community-generated data and insights that reflect what matters to the community and health-service users. For example, while regular M&E can focus on the number of clients served, CLM can provide insights on waiting times, stigma or discrimination experienced, or other reasons why clients choose not to visit services.

In this way, CLM is intended to fill the gap of many M&E systems from the client and community perspective. CLM and routine M&E are not interchangeable, and it is not required that they feed into a single database. CLM and M&E are, however, both part of the national M&E effort, and they complement and inform each other to generate a more comprehensive picture that helps improve service quality and access.

[1] See: Organizing framework for a functional national HIV monitoring and evaluation system. Geneva: UNAIDS; 2008 (https://www.unaids.org/sites/default/files/sub_landing/files/20080430_JC1769_Organizing_Framework_Functional_v2_en.pdf).

Question 5: Does community-led monitoring contradict the "Three Ones" principle[2]?

Answer: Not at all. CLM complements the one national M&E system, because CLM focuses on local fact-finding for problem-solving to meet the needs of local communities. The findings of CLM may inform the local and national M&E systems, but CLM data do not need to be stored in the national database. For data safety and security purposes, it may even be more beneficial to keep such data storage mechanisms separate and independent.

Question 6: Who owns community-led monitoring and its data?

Answer: The data from CLM are owned by community-led networks and groups. Data storage and access can be assured by a community-trusted and qualified technical support partner if the technical capacity is not already available in the affected community. Decisions on the sharing or non-sharing of data with stakeholders remains with the CLM leadership.

The principle of data confidentiality and security must be followed strictly throughout CLM. CLM data are frequently anonymized: in no case should individuals be identifiable through CLM data or community members placed at risk in settings where they could face prosecution or other harms.

CLM findings—such as issues and improvement solutions—can be made accessible for use by all stakeholders.

Question 7: Who are the key stakeholders of community-led monitoring?

Answer: The key stakeholders for CLM are community groups themselves. These include clients of the health services being monitored, members of the affected community who are or are not engaging with health services, and health- and rights-related civil society organizations and umbrella organizations. Partnerships with facility managers, health-service providers, government authorities at different levels, donor and development partners, and technical support agencies will enable CLM data to be effective in implementing change for HIV programme improvement.

[2] The "Three Ones" principles, established to ensure a harmonized, coordinated, and country-owned and led response to the AIDS epidemic are:

- One agreed HIV/AIDS action framework that provides the basis for coordinating the work of all partners.
- One National HIV/AIDS coordinating authority, with a broad-based multisectoral mandate.
- One agreed HIV/AIDS country-level monitoring and evaluation system.

See: The Global Task Team, a pathway to implement the "Three Ones". Guidance Note, UNAIDS, Geneva, 2005 (https://data.unaids.org/publications/irc-pub07/jc1225-guidancenote_en.pdf).

Question 8: Who can provide technical assistance to communities that are conducting community-led monitoring?

Answer: UNAIDS has prior experience with community-led organizations, civil society organizations and institutions that have a proven track record of supporting CLM processes and the direct implementation of CLM. These organizations include, but are not limited to, the International Treatment Preparedness Campaign (ITPC), Georgetown University's O'Neill Institute for National and Global Health Law, the Health Global Access Project (Health GAP), the Foundation for AIDS Research (AmfAR), and the West African Civil Society Institute on HIV and Health. As CLM expands, more groups will have the necessary experience to provide countries with quality technical support.

The selection of technical assistance providers in each country is determined by the community, specifically the networks of people living with HIV and their partners. To date, that selection has been based on existing relationships between the community and specific technical assistance providers (from other technical assistance processes and/or the implementation of other community-led activities). UNAIDS can help establish links between community groups and capable technical assistance providers.

Question 9: What technical resources are available?

Answer: Several agencies have produced technical guidelines about planning and implementing CLM. A Global CLM Technical Assistance Partners Forum has been established to promote consistency in the technical assistance that is provided to countries. Certain countries that have conducted CLM—such as South Africa and Uganda—are forerunners in providing such guidance. This can be adapted to fit the local context. UNAIDS is working on a virtual CLM resource hub where these and other information and experiences on CLM will be made available for public use.

Question 10: How can community-led monitoring be established in places where there is limited donor support?

Answer: Donor recognition and support of CLM has helped a number of countries establish CLM work and move it to scale. In countries where donor support for CLM is limited, UNAIDS country offices are expected to advocate and liaise with the government and community groups to amplify the unique value of first-hand routine data and information collection for the purpose of service quality improvement. This has been crucial for improving service provision in order to achieve nationally set HIV targets.

In places where there is limited donor support, in collaboration with stakeholders and partners, UNAIDS could identify key opinion leaders to promote the CLM concepts, mobilize catalytic support using the Joint Programme funding modalities and facilitate South–South collaboration. Starting the move in a modest way with small gains builds up trust and confidence in the hosting government's support for CLM. It also compliments regular programme monitoring and reporting. Experience shows that

mutual trust between the government and community groups is a critical enabler for CLM.

Efforts could also be made to check for other sources of support for CLM, including from government agencies from the United States of America, Germany and France, or from the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) and private foundations for start-up support for CLM.

Question 11: What does it take to make community-led monitoring sustainable?

Answer: Mechanisms to ensure national ownership of CLM are needed if it is to be sustainable. Perceptions that CLM is essentially externally funded and donor-driven reduce its sustainability. Community ownership and government appreciation of CLM—leading to their support for it—is the ultimate way of sustaining CLM.

It is important to note that CLM is not sustainable as a voluntary effort or one that is solely funded by donors and external partners. Instead, building technical capacity in communities will increase its sustainability. The greater the value that CLM can provide now, the more likely that buy-in and support will be generated among the government and other partners. It is imperative to showcase the valid and unique body of evidence that CLM can provide and its usefulness for improving services and health-related outcomes.

Question 12: Can community-led monitoring be performed in humanitarian and crisis situations?

Answer: Yes. CLM in humanitarian crises is a function of action and accountability by local community-led organizations of people living with HIV, networks of key populations and other community-led groups that gather quantitative and qualitative data concerning HIV services.

The role of community groups in humanitarian and crisis situations cannot be under-estimated. Donor support can be limited in humanitarian contexts, especially in the very early stages. The same is true of the felt presence of government and administration. History demonstrates that communities in these settings can themselves become providers of essential services and the source of pertinent and real-time insight to monitor their situation by drawing on local shared resources.

Data can be collected on disaster readiness and the distribution of HIV services. These data are used for monitoring trends at each stage of a disaster, with the aim of improving the overall quality, at least of the essential HIV services. CLM in humanitarian crisis contexts should build capacity, empower disaster-impacted communities, and elevate their role in the global disaster framework of action. Such contexts feature extremely challenging situations that can affect data collection, including but not limited to insufficient or absent power supply; restricted use of mobile technologies; data security issues (because most data collection is likely to be paper-based); and heightened risks and insecurity for marginalized groups collecting data.

Question 13: Will community-led monitoring cover other diseases?

Answer: CLM can contribute to monitoring trends in service quality within other disease areas (such as tuberculosis, malaria, mental health, and sexual and reproductive health) in humanitarian situations and challenging environments, and for social and structural health interventions (including combination prevention and human rights compliance, promotion and protection).

Question 14: How can UNAIDS help countries conduct community-led monitoring?

Answer: Engaging and supporting the leadership of communities and community-led organizations in HIV work is essential if UNAIDS is to fulfil its core mandate of acting as a global lead in the response to end the AIDS epidemic. As such, UNAIDS is committed to supporting CLM in order to empower community-led organizations and networks to participate in routine activities to improve service quality. This includes addressing structural barriers that reduce access to health services and working to improve the accountability of HIV programmes.

UNAIDS countries offices are expected to play a supportive role. This includes facilitating better communication between the government, community groups, donors and development partners, and enabling the technical support that community groups might need.

UNAIDS is publishing CLM guidelines and creating a virtual resource hub to promote quality CLM through the sharing of information and experiences. In collaboration with technical assistance providers, UNAIDS will also publish a toolkit to support community-led organizations to conceptualize, plan and implement CLM.

In several countries where UNAIDS is facilitating the funding of CLM and engaging in its programming, it can offer hands-on support to ensure the smooth and effective implementation of CLM by community groups.