



Independent observer  
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## Community-led monitoring of healthcare services: Addressing human rights and social justice in India and Indonesia

### What is Community-led Monitoring?

Community-led monitoring (CLM) is a mechanism to assess essential components of healthcare services and improve health outcomes of care recipients. In the context of the HIV response, CLM allows care recipients to collect and own their data, identify gaps, generate actionable evidence, and advocate to improve HIV-related health services. By providing insights about the state of a local or national HIV and associated health response, CLM assists program and facility managers and policy makers to improve essential service components under the framework of availability, accessibility, acceptability, and quality (AAAQ) [1]. CLM is increasingly being seen by stakeholders as a tool to monitor facilities and services with a growing interest in technical and funding resources from organizations and donors, including the International AIDS Society, the Joint United Nations Programme on HIV/AIDS (UNAIDS), the Global Fund to Fight AIDS, TB, and Malaria, and the United States President's Emergency Plan for AIDS Relief (PEPFAR) [2, 3, 4, 5]. CLM efforts also have helped communities address social justice and human rights, programing gaps in treatment literacy, and retaining people in care and treatment.

### Community-led Monitoring Project in Asia

To assess the status of established national HIV programs and the evolving national viral hepatitis programs, the Community-led Monitoring Project in Asia [6] was initiated in 2021 by the Community

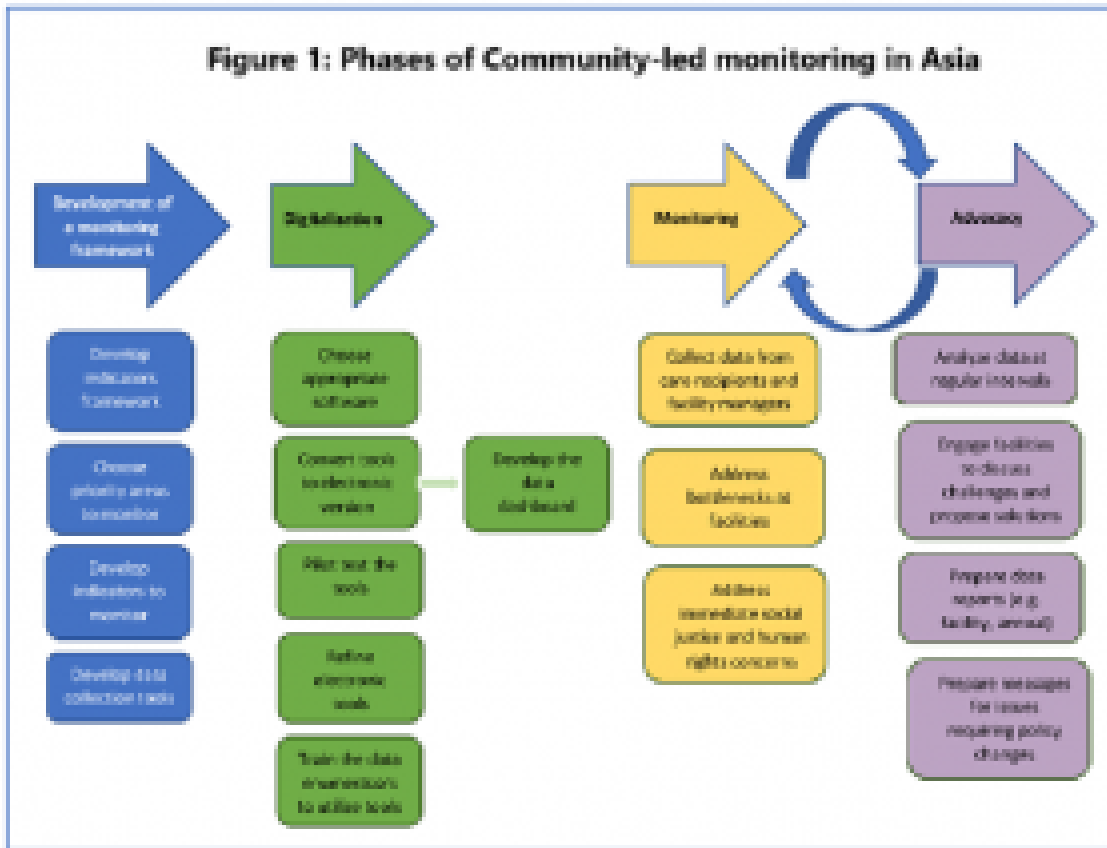
Network for Empowerment (CoNE) in Manipur, India, Yayasan Peduli Hati Bangsa in Indonesia, the International Treatment Preparedness Coalition – Global (ITPC), and amfAR’s TREAT Asia program. CoNE and Peduli Hati are monitoring a total of 12 health facilities, covering both HIV and viral hepatitis clinics within these facilities, from local districts to referral hospitals that provide public sector services for HIV and viral hepatitis care in Manipur, India, and Indonesia. The CLM indicators, developed by people living with HIV (PLHIV), people who use drugs (PWUD), and peer team members from the two organizations, are based on current national guidelines and policies, and target essential components of the AAAQ framework covering HIV, hepatitis B (HBV), and hepatitis C (HCV). From 2021 to 2024, CLM in Asia received financial support from ViiV Healthcare and amfAR.

## Digital Platform

In April 2023, the project transitioned to a digital platform with the technical support of amfAR’s Andelson Office of Public Policy. It is one of the first CLM projects in the Asia-Pacific region to make real-time data publicly available through an online dashboard, and is the only global CLM project where indicators for HBV and HCV services have been developed and are being monitored. As various CLM projects are developed, a key focus is on enhancing the digitalization of data collection and information-sharing through dashboards. There is significant potential to leverage the expertise within the CLM in Asia project to share knowledge and skills with others looking to implement or advance the digitalization of CLM platforms.

Understanding the process of developing a monitoring framework in its initial phase—where community members engage in discussions to define their monitoring priorities and desired outcomes—is vital for effectively transitioning to digital solutions and successful advocacy efforts that address key issues. The implementation of the project involved components across four phases, as described below (Figure 1).

**Figure 1: Phases of Community-led monitoring in Asia**



1. **Development of a monitoring framework:** In the first phase, individuals from the PLHIV and PWUD communities discussed the problems they encounter in healthcare settings and prioritized the areas they wanted to monitor. Qualitative and quantitative indicators were framed and further developed in the form of tools [7] that were used for data collection.
2. **Digitalization:** Digitalizing data collection and reporting processes facilitated engagement with care recipients and real-time availability of data. The CommCare™ software platform was chosen to enable digitalization on the basis of its ease of use, data security, possibility of off-line data collection, and adaptability for use with tablets and mobile phones. Pilot testing of the tools through mock data collection was conducted and necessary changes in the software settings and indicators or answer options were made. Data enumerators were trained on the data collection and submission processes using the digital platform.

A data dashboard was developed that synchronizes uploaded data in real time [8, 9]. The dashboard generates data visualizations through graphs and figures. This makes it easier to communicate findings to facility managers and decision makers to support advocacy around gaps in the quality of care reported by the care recipients.

3. **Monitoring:** This phase initiated the process of reaching out to care recipients and facility managers using tablets or mobile phones for collecting data. Real-time internet connectivity was not required during the process as the software stores data and synchronizes with the dashboard when the data enumerator has internet access. The data collection process not only recorded user responses to questions about the care they were receiving, but also served as an opportunity to hear about people's inability to access services, concerns about social justice, or human rights violations. The community partners were able to rapidly initiate advocacy efforts to address shortcomings that needed immediate attention. Efforts to address some of the broader social justice or human rights issues commenced immediately or soon after the data collection process [10].
4. **Advocacy:** Insights from monitoring are utilized to drive adjustments in facility operations and broader policy decisions. Meetings with facility managers and decision makers were organized quarterly, or more often as needed, to communicate findings and co-create solutions to the issues. Reports on individual health facilities can be generated from the dashboard and shared with the facility managers to help them understand how care recipients perceive the services.

Compared to the paper-based data collection and storage used until 2022, digitalization of the CLM methods enabled more rapid monitoring and immediate data visualization and increased the number of care recipients the CLM teams could engage with over time. From April 2023 to October 2024, the nine data enumerators in the project reached out to 3,415 care recipients, compared to 120 people reached through interviews and focus group discussions between January and December 2022. Among those responding in the digitalized CLM data collection process, 2,609 (76%) were 25–49 years of age, 73% were male, 27% were female, and 0.003% were transgender people. Respondents were receiving care for HIV (65%), HBV, (1.8%), and HCV (33%).

Though CLM is primarily viewed as a mechanism for monitoring health facilities, including stockouts of medicines and diagnostic tests, we have found that it also enhances education about diseases for care recipients, evaluates their understanding of legal safeguards, and addresses human rights and social justice through rapid response systems. All these broad benefits of CLM come at a crucial time when investments in treatment literacy, preparedness, and support for care recipients have been on the decline.

From April 2023 to October 2024, the project led to the improvement of care services, ensured supply of medicines and diagnostics tests, and facilitated advocacy around human rights and social justice. Major broad benefits of CLM include various aspects of ensuring access to healthcare services and retention in care, while addressing human rights and social justice. Some of the specific achievements in India and Indonesia are discussed below.

- i. Routine viral load testing for HIV is intended for all individuals on treatment, but this is not always achieved despite the efforts of healthcare facilities and community groups. PLHIV who had missed their scheduled testing dates were linked to viral load testing.

- ii. Index testing has been promoted to ensure that all family members and partners are properly diagnosed and connected to either prevention or treatment services.
- iii. The “Treat All” policy for HIV has been established as a national policies for several years. However, not all individuals with a confirmed HIV-positive status seek treatment for various reasons. During the data collection process, PLHIV were identified who had not yet started ART and were linked to treatment.
- iv. Retention in HIV care and treatment is crucial to prevent resistance to antiretroviral medications and to avoid progression to advanced HIV disease or associated mortality. During the data collection process, individuals who had dropped out of HIV treatment were identified and successfully re-initiated on treatment at their respective ART centers.
- v. Since 2012, HBV vaccination has been recommended for high-risk groups, such as PWUD. However, this has not received significant attention. HBV is a leading cause of cirrhosis, liver cancer, and associated mortality. To prevent such adverse outcomes, unvaccinated people were provided with the full 3-dose vaccine series.
- vi. Elimination of HCV as a public health target by 2030 is underway, with both India and Indonesia having launched national programs focused on viral hepatitis. However, not all people are aware of the services or walk into centralized public care centers to access services. Individuals received various services related to HCV including RNA viral load testing, treatment, re-treatment, and sustained virological response (SVR 12) testing to confirm a cure.
- vii. Maintaining a regular supply of medicines and treatments is essential for ensuring that care recipients have uninterrupted access to services. The CLM teams successfully averted or resolved 10 instances of stockouts or shortages of HIV and HCV medications through their interventions.
- viii. Differentiated service delivery and easy access to treatment centers are crucial for retaining individuals in care and treatment. Data enumerators advocated for various strategies to enhance service accessibility, resulting in PLHIV being linked to treatment centers closer to their locations, thereby facilitating retention.
- ix. Children living with or affected by HIV were linked to social security schemes providing financial support for their education.
- x. CLM is emerging as a mechanism to address rights violations. Through efforts of the CLM teams, cases of human rights violations, stigma, and discrimination were addressed.

CLM in Asia has proven to be an effective approach to monitor the quality of care in participating healthcare facilities and driving positive changes in addressing social justice and human rights and filling programming gaps in treatment literacy. For any CLM-associated activity to deliver optimal impact, we recommend:

- i. Use of monitoring frameworks that prioritize essential indicators to minimize burdens on data enumerators.
- ii. Investment in digitalization of tools and an online dashboard to facilitate real-time data visualization to optimize use in advocacy.
- iii. Support for data enumerators for their time, mobile internet data airtime, travel during data collection.
- iv. Use of CLM platforms to address broader challenges, including identification of human rights violations and facilitating redress.

CLM and its broad benefits can also play a critical role in addressing urgent individual-level human rights and care access issues in a more rapid timeframe through effective co-problem-solving and advocacy.

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