SK PA·2

COMMUNITY LED MONITORING

Transitioning from Pilot Projects to Sustainable Scale up in Bhutan, Mongolia, and Sri Lanka

November 2023

HEALTH EQUITY MATTERS

The Sustainability of HIV Services for Key Populations in South-East Asia (SKPA-2) is a three-year program (1 July 2022 and 30 June 2025), aimed at improving the sustainability of evidence-informed, prioritized HIV services for key populations in Bhutan, Mongolia, the Philippines and Sri Lanka. The objectives of SKPA-2 are to: accelerate financial sustainability; improve strategic information availability and use; promote programmatic sustainability; and remove human rights- and gender-related barriers to services.

SKPA-2 APPROACH TO COMMUNITY LED MONITORING

Community led monitoring (CLM) contributes to strengthened national HIV responses and to meeting the goal of ending HIV. Implementation of CLM has achieved improvements in service delivery at facility and district levels and strengthened health systems. As noted by Baptiste *et. al,* the most successful CLM models are characterized by strong community leadership and engagement, linked to advocacy and action plans to address the findings.[1]

SKPA-2 defines CLM as: "*...an ongoing process in which service users or local communities gather, analyze and use information to support quality improvement of HIV services and advocacy efforts to increase uptake of and retention in HIV and related health services and, ultimately, to improve health outcomes for key populations.*"[2]

SKPA-2's approach to scale up is informed by the Global Fund's CLM guidance[3], the CLM process cycle in the SKPA-2 CLM toolkit (**Figure 1**), and the findings from the SKPA-2 CLM of HIV services for key populations toolkit pilot in Bhutan, Mongolia and Sri Lanka.[4]

This concept paper summarizes lessons learned from piloting the toolkit and outlines key program activities to support the scale up of CLM.

In 2023, SKPA-2 launched the CLM toolkit which presents an approach to measuring the quality of HIV services for key populations from the perspective of service users and includes an overarching framework, indicators and data collection tools that can be adapted to the country context.

Find more information on the toolkit Scan QR code or **click here**.

[1] https://link.springer.com/article/10.1007/s11904-020-00521-2
[2] https://healthequitymatters.org.au/wp-content/uploads/2022/08/SKPA2-CLM-Toolkit-2022.pdf
[3] https://www.theglobalfund.org/media/9632/crs_2020-02cbmmeeting_report_en.pdf
[4] https://healthequitymatters.org.au/wp-content/uploads/2022/08/SKPA2-CLM-Toolkit-2022.pdf

Figure 1.
Community Led Monitoring Process Cycle

Importantly, CLM empowers service users and is a critical component of community engagement in HIV program delivery. The Availability, Accessibility, Acceptability and Quality (AAAQ) framework[5] (**Figure 2**) enables community- and key population-led organizations to assess the services they receive based on the many factors that affect key populations' experience of using HIV services. The indicators generated from these efforts are designed to be complementary to rather than duplicative of the standard HIV indicators routinely monitored by the health system.

[5] https://www.ohchr.org/sites/default/files/Documents/Issues/ESCR/Health/RightToHealthWHOFS2.pdf

Figure 2.
Conceptual Framework: Availability, Accessibility, Acceptability and Quality (AAAQ) Framework

Insights from these indicators are important because any one of these Availability, Accessibility, Acceptability and Quality factors may be a deterrent to an individual maintaining their HIV negative status or adhering to ART.

CLM work under SKPA-2 is focused on the utilization of a range of HIV services, including prevention, with data generated by individuals who have used one or more HIV services recently. This contrasts with some CLM tools which focus almost exclusively on treatment. Under SKPA-2, CLM also captures experience of stigma and discrimination and other human rights violations. These are treated as `serious incidents' and require follow up and adequate case management and service referrals for the affected individuals who consent to being followed up.

PILOTING THE SKPA-2 CLM TOOLKIT AND LEARNING LESSONS

The SKPA-2 CLM pilot ran from October 2022 to June 2023 in Bhutan, Mongolia and Sri Lanka, with strong support from community members. The pilot assessed the feasibility of the CLM framework, process and indicators (**Table 1**) and identified lessons to inform scale up. Learning from the pilot in these countries also contributes to the evidence base globally, and in the region, where the HIV epidemic disproportionately impacts key populations.

Table 1. CLM indicators, SKPA-2 CLM toolkit

Indicator number	Short name
A1.	CLM participation
A2.	HIV service availability
A3.	HIV service accessibility
A4.	HIV service acceptability
A5.	HIV service quality
A6.	HIV service satisfaction
A7.	Prevalence of serious incidents
A8.	Prevalence of stigma and discrimination (subset of A7)
B1.	Serious incident follow-up attempts
B2.	Successful client follow up of serious incidents
B3.	Accurate reporting of serious incidents
B4.	Referrals to services following a serious incident
B5.	Successful and timely resolution of serious incidents

Lessons Learned

The pilot found that the SKPA-2 CLM process was feasible *provided the toolkit was adapted to different local contexts*, including translation into local languages.

The pilot highlighted the importance of ensuring the tools are field tested and understood by community members before moving to scale up, and of involving health facility management in discussions on CLM early on.

Other lessons include:

- Early investment in stakeholder dialogue and advocacy is needed before commencing the CLM process.
- Appropriate ethical clearance and institutional permission must be obtained before starting CLM, and these approvals must be formally communicated to facility staff.
- Implement CLM sensitization and demand generation for health facility staff and key populations through orientation workshops and flyers and booklets in local languages.
- Simplify CLM client forms to ensure clients can answer all questions without assistance.
- Support and build a culture of utilizing CLM data to inform advocacy for policy change and to improve service quality and delivery.

The recommendations from the pilot together with stakeholder feedback will inform an upcoming revision to the SKPA-2 CLM toolkit in 2024. Having successfully shown that data for a standard set of AAAQ indicators can be reliably collected and analyzed in different country settings, SKPA-2's focus will be on developing country-specific CLM models and exploring how these models can contribute to a sustainable national HIV response.

Key Considerations for Scaling up and Increasing Impact

SKPA-2 promotes solutions that are sustainable, low cost, community-owned and led and that maximize participation in CLM. Key issues that need to be considered include:

- Whether to conduct CLM periodically using a time-bound survey or on an ongoing basis.
- Whether to use a paper-based or electronic system for CLM data collection.
- Whether to use an open source or proprietary data management system.
- Whether to strengthen an existing government-owned feedback mechanism or establish one that is community-owned and led.

Table 2 provides an overview of the pros and cons of each option, together with the option recommended by SKPA-2, which is **bolded** in the Table.

Table 2. Community Led Monitoring Sustainability Consideration

CLM Sustainability Consideration	Option	Pros	Cons	SKPA-2 Recommended Option
Conduct CLM periodically as a survey vs promote CLM for any service recipient and visit	Conduct CLM periodically as a survey	Allows for training key populations as expert clients Increased control over data quality	Limited participation Insights may not be representative Will miss important incidents that occur between survey rounds	
	CLM is open to all on a routine basis	Equitable participation and more representative data Larger dataset for more sophisticated analysis	Challenges with larger dataset including more potential errors, resources may be needed to manage and cleaning the data	✓
Paper-based vs electronic CLM data collection	Paper-based data collection	Simple and ability to use offline	Printing costs Limits participation Resources and time required for data entry and analysis	
	Electronic data collection	Automatically tallied and transformed into analysis; Issues can be identified in real time	Requires ICT infrastructure such as smartphones, computer or tablets, and skills; and data management platform	✓
Open-source vs proprietary data management system	**Open-source data collection and management**	Low cost Adaptable, can be more easily modified locally	Requires more programming to be fit for purpose; interfaces not as attractive	✓
	Proprietary data collection and management	High quality design, high quality outputs	Expensive; Adaptations and going to scale require more time and often requires external TA and specialist support	
Strengthen existing government-owned feedback mechanism vs establish one that is community-owned and led	Strengthen government-owned feedback system	Low cost Methods such as suggestion boxes already in place Can be improved with greater key population engagement	Not community led Lack of trust regarding anonymity, confidentiality and the use of feedback	
	Establish CLM that is community-owned and led	Promotes equity and represents the voice of key populations Greater reliability of data through perception of independence and impartiality	Set up and recurrent costs Difficult to attract government funding if government is invested in its own feedback system	✓

SKPA-2 Scale-up Implementation Framework

Learning from the pilots, scale up of CLM in each country will depend on several factors including epidemiological context such as where the HIV epidemic is concentrated, together with practical considerations like availability of resources, willingness to participate, and capacity to implement CLM.

Table 3 presents a Scale-up Implementation Framework across three main categories: CLM scale up, CLM demand generation, and CLM sustainability strategy. This framework is designed to inform planning and budgeting and needs to be adapted locally through a CLM Technical Working Group or oversight committee that includes key population representatives.

Table 3. CLM Scale up Implementation Framework: Key Steps and Activities

Implementation Area of Work	Key Steps and Activities
CLM Scale Up	**Stakeholder Engagement and Strategic Partnerships**
	Establish a CLM Technical Working Group (TWG) to include at least one representative from each relevant key population group affected by HIV, the National HIV Control Program and any other relevant organizations that may support CLM implementation. *While it is important to have government representation, key population representatives should lead on decision making.*
	Identify a lead organization for CLM implementation (usually a key population-led organization).
	Establish strong partnerships with other community-based organizations, key population-led organizations and groups involved in HIV service delivery.
	Establish or strengthen partnerships with government agencies and other national Stakeholders.

Implementation Area of Work	Key Steps and Activities
CLM Scale Up	**Data Collection Design and Implementation**
	Convene regular CLM TWG meetings and consultations to support design and day-to-day implementation of CLM.
	Conduct training on data collection for key population-led organizations and other relevant key stakeholders
	Develop Memoranda of Understanding or partnership agreements with relevant health facilities and agencies to support data collection (as required).
	Develop Standard Operating Procedures to support data collection, analysis and use, ensuring confidentiality and data protection in line with international and national standards.
	Provide technical assistance to support the selection and development of a system for electronic data management, entry, and storage for CLM client forms along with the development of an electronic dashboard for use by the community and CLM program implementors to improve real time use of CLM data to inform action planning and use of data for decision making.
	Implement CLM data entry using online data collection forms that are adapted based on the pilot feedback.
	Establish data security protocols to protect CLM participants anonymity and confidentiality
	Establish CLM data collection arrangements for those unable to utilize online data collection forms (e.g., for low literary and illiterate CLM clients).
	Adapt the client satisfaction tool for serious incident management.
	Finalize and roll out Serious Incident Follow-up, including agreements with referral network partners, develop referral forms and provide training where needed
	Train supervisors and key population focal points on the CLM Serious Incident Follow-up protocols and process.

Implementation Area of Work	Key Steps and Activities
CLM Scale Up	**Data Analysis**
	Provide technical assistance to support data analysis and writing of CLM quarterly reports.
	Hold consultative workshops with key population organizations, community members and government representatives to support development of CLM electronic data systems and digital dashboard systems.
	Data use for quality improvement and advocacy
	Train key population-led organization representatives on use of the online CLM data platform/dashboard.
	Train supervisors and key population focal points on the CLM Serious Incident Follow-up protocols and process.
	Support the development of quality improvement plans at site level in response to CLM findings – these plans may be developed through site visits or joint action planning workshops with health facilities, key population representatives, CLM clients, and government stakeholders.
	Support the implementation of specific quality improvement activities at site level that are prioritized in the evidence-based CLM action plans.
	Conduct an annual CLM national review meeting.
	Support the identification of common barriers faced by key populations through cross-site analysis of CLM data that can be used for advocacy purposes.
	Implement advocacy activities at above site level (e.g., district/regional/national).
	Show recognition of best practice sites based on client feedback.

Implementation Area of Work	Key Steps and Activities
CLM Demand Generation	Conduct sensitization/workshops with health facility staff on CLM to build understanding and increase buy-in for CLM participation.
	Develop CLM materials and CLM demand generation activities.
	Develop communication products using CLM results to showcase how CLM improves HIV services and generate buy-in for CLM among key stakeholders and key populations.
	Integrate CLM data collection forms into social media platforms and relevant websites.
CLM Sustainability Strategy	Provide technical assistance to review CLM national implementation and develop a CLM sustainability strategy, including outlining costs required, roles and responsibilities and other considerations for long term sustainability.
	Hold a national consultation with key population representatives, government stakeholders and health providers to develop and finalise the CLM sustainability strategy.

Conclusion

CLM is yet to live up to its potential because current efforts have been mostly small scale and fragmented. With the majority of the CLM literature based on experiences in Sub-Saharan Africa, CLM work in SKPA-2 presents an exciting opportunity to develop Asia-specific CLM models and expand the evidence base with insights from this region. With the impact of HIV focused on key populations and the unique challenges these communities face, experiences from CLM in the Asia Pacific region will be important for building understanding among communities and governments on how to design and implement key population-friendly HIV services. Understanding barriers and experiences from the perspective of service users is critical to driving quality improvement and more equitable access to HIV services.

Collaboration is key to CLM success, and this will increase learning and cross-fertilisation of ideas and contribute to the development of Asia-specific models on CLM. At regional level, SKPA-2 is working with the UNAIDS Regional Support Team and collaborating with the Seven Alliance, a consortium with membership from APCOM, APN+, APNSW, APTN, ICWAP, NAPUD, and Youth LEAD. Each network in the consortium plays a vital role in the regional response to HIV[6]. The Asia Pacific Council of AIDS Service Organizations (APCASO) is also supporting regional CLM activities for TB that may provide further opportunities for collaboration and sharing to ensure integration between CLM for HIV and TB.

Collaboration at country-level involving multiple stakeholders is key to the success of CLM. CLM data should be driving dialogue between key populations, key population-led organisations, and health care workers delivering HIV services in the spirit of partnership towards better quality, client-friendly and effective HIV services. The long-term success of HIV epidemic control efforts depends on community leadership and empowerment.

[6] https://www.sevenalliance.org

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