COMMUNITY LED MONITORING IN SRI LANKA

Pilot Project Technical Brief

January 2024

HEALTH EQUITY MATTERS

Sustainability of HIV Services for Key Populations in South-East Asia (SKPA-2) is a three-year program (1 July 2022 to 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.

INTRODUCTION

HIV prevention and treatment programs for communities most affected by HIV can achieve greater improvements in HIV-related outcomes when delivered through community-led models.[1] Adapted from the Global Fund's definition, SKPA-2 defines community-led monitoring (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 CLM is one of the first to focus on assessing the quality of key population HIV prevention and treatment services in Asia using an adapted version of the Availability, Accessibility, Acceptability and Quality Conceptual Framework[3] (**Figure 1**). The framework uses data collected from individuals belonging to one or more key population groups who have used HIV services recently.

Figure 1. Adapted Availability, Accessibility, Acceptability and Quality Framework

[1] Ayala, George, et al. "Peer-and community-led responses to HIV: a scoping review." PLoS One 16.12 (2021): e0260555. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0260555
[2] https://healthequitymatters.org.au/wp-content/uploads/2022/08/SKPA2-CLM-Toolkit-2022
[3] https://www.ohchr.org/sites/default/files/Documents/Issues/ESCR/Health/RightToHealthWHOFS2.pdf

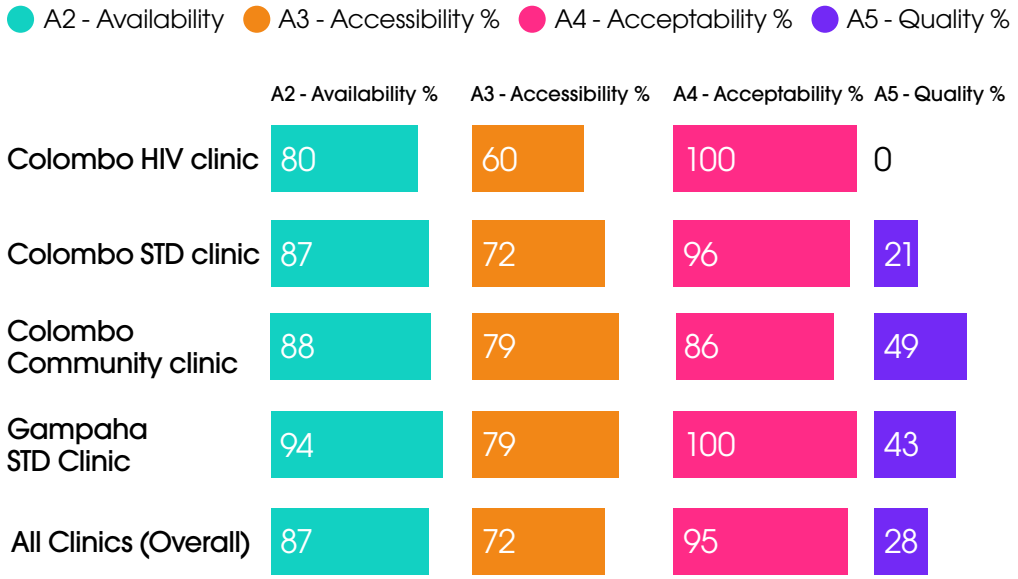
METHODOLOGY

The CLM pilot project commenced in November 2022 through the launch of a CLM Technical Working Group (TWG) and the adaptation of the SKPA-2 CLM toolkit including translation into Sinhala and Tamil. The CLM process is managed by Family Planning Association of Sri Lanka (FPA-SL) and, for the pilot process, Lanka Plus, an organization led by people living with HIV. The CLM TWG provided strategic oversight of the process with representatives from key populations, the National STI/AIDS Control Programme (NSACP), and FPA-SL. Data were collected in June 2023 from men who have sex with men in four service delivery sites, to assess the feasibility and acceptability of the SKPA-2 CLM process. The sites included three government clinics (Colombo STD clinic, Colombo HIV clinic, Gampaha STD clinic) and one community clinic (Heart 2 Health Colombo). Site selection was decided by the CLM TWG and the Director of the NSACP. Data were collected through the CLM Client form, administered through trained data collectors hired and overseen by Lanka Plus together with a consent form, and the CLM Follow-up form, completed by a Case Manager for those clients who reported a serious incident and consented to follow-up by trained staff. A total of 133 men who have sex with men participated in the CLM pilot, including 6 (4%) who engaged in sex work, 18 (13%) who used recreational drugs and 3 (2%) who injected drugs. More detailed information may be found in the pilot report[4] or SKPA-2 CLM toolkit[2].

RESULTS

The pilot results are presented according to the Availability, Accessibility, Acceptability and Quality variables along with the Serious Incidents and Serious incident follow-up indicators outlined in Table 1. The AAAQ scores (**Figure 2**) are presented for each service delivery site along with the overall scores across all facilities under the pilot (**Table 1**). Acceptability ranked highest (95%) followed by Availability (87%), Accessibility (72%) and Quality (28%).

Figure 2. CLM Availability, Accessibility, Acceptability indicator by clinic location



Source: SKPA2 CLM Pilot #1: May - June 2023

[4] Family Planning Association of Sri Lanka, 2023. Community-led Monitoring of HIV Services in Sri Lanka; Report of the pilot project 2023, Colombo.
[2] https://healthequitymatters.org.au/wp-content/uploads/2022/08/SKPA2-CLM-Toolkit-2022

Table 1. CLM Indictors

Indicator Short Name	Results
A1. CLM participation (Total) • Colombo HIV clinic • Colombo STD clinic • Colombo Community clinic • Gampaha STD clinic	133 • 10 • 53 • 54 • 16
A2. HIV service availability	87 %
A3. HIV service accessibility	72 %
A4. HIV service acceptability	95 %
A5. HIV service quality	28 %
A6. HIV service satisfaction	9 (out of 10)
A7. Prevalence of serious incidents	3 % (4 clients)
A8. Prevalence of stigma and discrimination	1.5 % (2 clients)
B1. Serious incident follow-up attempts	50 % (2 clients)
B2. Successful clients follow up of serious incidents	50 % (2 client)
B3. Accurate reporting of serious incidents	100% (2 out 2)
B4. Referrals to services following a serious incident	0
B5. Successful and timely resolution of serious incidents	100% (2 clients)

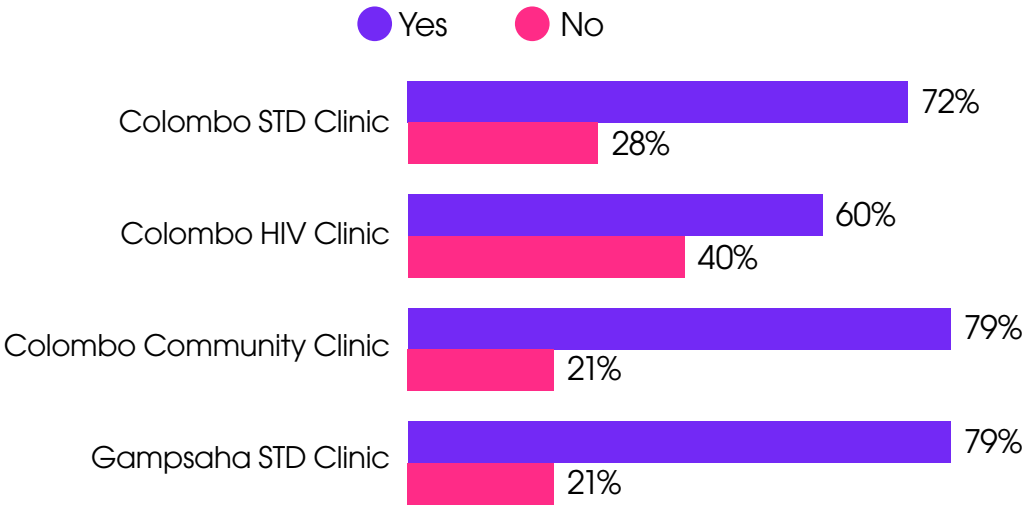
A2. HIV Service Availability

HIV Service Availability was measured by taking the number and percentage of users that received all the HIV and health services they sought. Availability of HIV services was very high at 87% overall. Gampaha STD clinic scored the highest on availability at 94%, and no sites scored lower than 80%. Except for one client, all participants who sought HIV screening or confirmatory testing received the service. The main gap in service availability related to condoms and lubricant, which was lowest at the Colombo STD clinic (68%) where five participants did not receive them, compared to around 90% at the other sites. Availability of STI services was nearly 100%. Availability of ART services was also high, although two participants were not able to obtain ART refills (one each at Colombo HIV clinic and Gampaha STD clinic), and one was not able to be initiated on ART (Colombo STD clinic). All 17 participants who sought PEP received it, and all except one of the 56 persons who sought PrEP received it. Despite the impact of the country's economic situation on public sector funding, the results of the pilot suggest that the availability of HIV services in Sri Lanka is high.

A3. HIV Service Accessibility

HIV Service Accessibility was measured using four different variables – 1) convenient location, 2) safe location, 3) suitable opening hours and 4) affordable services – and all four had to be in place for the service to be rated as accessible. Overall HIV service accessibility was rated as 72%, with scores for the four sites ranging from 60% to 79%. The main barrier to accessibility was cost, with 25 (18%) of participants reporting that services were not affordable. The details of service affordability by clinic location are presented in **Figure 3**. A small proportion said that opening hours were not suitable (3%) or that the location was not safe and convenient (4%). The economic situation in the country has made the cost of living and access to medicines a struggle for many in Sri Lanka. Actions to help address the cost barrier, including vocational and training programs for key populations, have been identified.

Figure 3. Service Affordability



Source: CLM Pilot Data – June 2023.

A4. HIV Service Acceptability

HIV Service Acceptability was measured using three different variables – 1) client treated respectfully, 2) consent was sought and 3) privacy and confidentiality was met – and all three had to be in place for the service to be rated as acceptable. HIV service acceptability scored highest among the AAAQ indicators at 95% overall, with scores ranging from 100% at the Colombo HIV and Gampaha STD clinics to 86% at the Colombo community clinic. Feedback from one participant shows a high level of appreciation for the staff when asked about the best part of the experience at Colombo STD clinic:

"they have accepted us well and treated us lovingly".

A5. HIV Service Quality

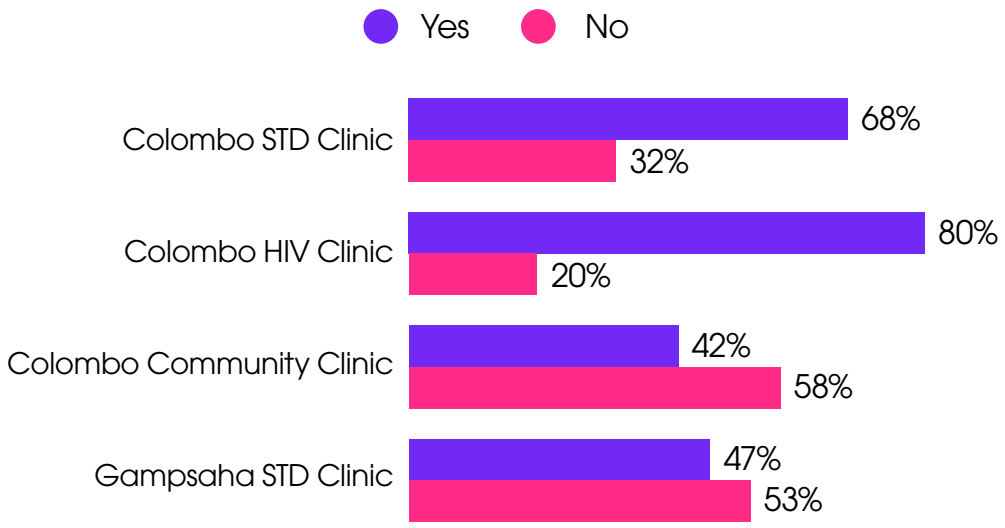
HIV Service Quality was measured through three different variables – 1) the client received all items or commodities they needed (e.g. medicines, condoms), 2) the client did not have to wait 'too long' to see a healthcare provider and 3) all the information they needed was received – and all had to be in place for the service to be rated as quality. HIV service quality scored lowest among the AAAQ indicators at 28% overall. Of the three variables, waiting time was most responsible for reducing the overall score with around half of all participants reporting they had to wait too long for the HIV service as illustrated in **Figure 4**. Through discussions during data analysis, it also became clear that the question was too open ended and might be better rephrased to include a specific benchmark waiting time that can be considered reasonable. Twenty participants reported not receiving one or more items or commodities they needed, which affected the overall quality score. Half of these (10 out of 20) were clients of the Colombo STD clinic. Only four participants reported not receiving all the information they needed, or not having all their questions answered.

A6 HIV Service Satisfaction

When asked to give a score out of 10 for overall service satisfaction, respondents scored all services highly, with a mean score of 9 out of 10. Scores ranged from 9.6 for Gampaha STD clinic to 8.7 for Colombo HIV clinic. The higher satisfaction rating for Gampaha STD clinic is consistent with the clinic scoring the highest on availability, accessibility, and quality indicators. Gampaha also had the lowest proportion of clients reporting waiting too long for the service. At other sites the very high satisfaction score, contrasted with the low quality score, suggests that lengthy waiting time did not have a significant impact on overall satisfaction with the services. However, these comparisons should be reviewed with caution as only 16 participants were included from Gampaha STD Clinic.

Figure 4. Perceived Acceptability of Waiting Time

Response to the question, "Did you have to wait too long to see the healthcare provider?



Source: CLM Pilot Data – June 2023.

A7-A8.Serious Incidents including Stigma and Discrimination

Serious Incidents identified during the pilot phase were low with four cases identified (2.9%) out of 133 CLM clients – there were three reports of stigma and discrimination and one where a client objected to excessive and personal questions related to their sexual behavior.

> *"Unnecessarily persistent questioning including… asking personal questions about my partners and role/positions when engaging in sex."*

Two of the four cases consented to follow up. The first, a client who had reported stigma and discrimination and breach of privacy/ confidentiality – an employee at the clinic (not involved in service delivery) had told people in the neighborhood that he had attended a medical examination at the clinic (which is known as a HIV/STI clinic – was followed up by the pilot CLM coordinator. The client feared reprisals if any action was taken and declined escalating the incident. The second case, where the client had objected to questions about their sexual behavior, was also followed up by the CLM pilot coordinator. Again, the client declined to pursue the matter further due to concerns that returning to the same clinic might lead to an uncomfortable situation, while indicating their preference to see a different doctor if they were to return to the same clinic. The CLM process takes a survivor-centered approach and respects clients wishes when conducting follow-up. SKPA-2 will continue to build trust with communities and strengthen referral pathways so that future incidents can be resolved and include referral for additional services as needed. It will also be important to strengthen procedures for addressing serious incidents within health facilities, including with the healthcare providers reported through CLM.

RECOMMENDATIONS

Since the pilot, a CLM plan has been developed to support a phased approach to nation-wide scale up of CLM for HIV programming. Use of the data collected through the pilot have been accepted by key stakeholders including key population organizations, NSACP, and health facility staff and leadership. Ultimately the value and sustainability of CLM requires communities participating to know that their voices are being heard and that their feedback is used to improve services. There are encouraging signs that this process has commenced at the sites involved in the pilot including developing site level action plans with each of the four clinics. The pilot has also facilitated improvements in specific aspects of service delivery with some recommendations from the pilot already being implemented including enhanced privacy during consultations through purchase and installation of privacy screens; improved staff attitudes to clients including more attention being paid to welcoming and greeting clients; and improved queue management to reduce the time that clients have to wait in the clinic before seeing a provider.

Based on the findings of the CLM pilot, the following recommendations have been highlighted:

- Expand CLM to additional key populations including transgender people and female sex workers.
- Simplify the CLM form using language that is accessible to a general audience.
- Develop a simplified and easy to read CLM community report or dashboard that can be used for real-time action planning.
- Develop national CLM standard operating procedures (SOP).
- Ensure clear understanding of and buy in to CLM from clinic staff and key populations through advocacy, dialogue and communication.
- Develop CLM sensitization and Information, Education and Communication (IEC) materials in multiple languages and formats including flyers, and booklets.
- Use CLM results in meetings with health facilities to highlight gaps in services and propose quality improvement plans and activities.
- Strengthen the reporting and management of serious incidents for the protection of clients and for friendlier, non-discriminatory, and safe services.
- Consider developing a case study or organizing a learning visit to Gampaha STD clinic so other clinics can understand the factors that contribute to its high scores.

CONCLUSION

The pilot showed that the overall framework, methods, and process were feasible, but that the toolkit needed to be adapted to suit the local context (including translation into local languages) together with ensuring that that the tools are field tested and understood by community members before moving to scale up. The pilot was successful in testing the data collection, analysis and report writing. It also identified the need to build a stronger culture of data use and for adequate funding and capacity building to be included in CLM planning beyond data collection and report writing.

The pilot found generally high appreciation of HIV services by men who have sex with men in Sri Lanka. The highest scores under the AAAQ framework were for Accessible services (95%) followed by Available services (87%), Acceptable services (87%), and finally Quality (36%). Factors that contributed to low quality included long wait times due to staff shortages and shortages of commodities during the data collection timeframe, in some cases exacerbated by the economic crisis and post-COVID challenges that Sri Lanka is currently facing. However, service quality also depends on many other factors including, for example, the skills of medical and non-medical staff, and so the pilot results should be interpreted with caution. With these limitations in mind, the results provide some important feedback from key population service recipients. The Gampaha STD clinic scored the highest on all AAAQ indicators and on client satisfaction, suggesting that the AAAQ indicators selected are directly related to the satisfaction of key population HIV service users. The results also provide an evidence base for learning from good practices at the Gampaha STD clinic and replicating these at other sites. The apparent disconnect between low quality scores and high satisfaction may need to be investigated further and, if the service quality variables are not strongly linked to overall satisfaction, there may be a need to improve on the construction of the service quality metric.

The pilot results highlight isolated but concerning incidents of individuals being unable to initiate ART or obtain ART refills, a finding which was not classed as a serious incident in the toolkit but needs to be fed back to the clinics concerned and NSACP management. The pilot also found that serious incidents are uncommon, but that the procedures for dealing with them when they arise require improvement, both to ensure the privacy and confidentiality of clients is protected after reporting serious incidents, and accountability for provision of non-discriminatory services by healthcare providers and facilities. The conclusions are offered in the spirit of partnership between community members and health authorities towards a stronger response to HIV, human rights, and gender.

CONSIDERATIONS

- The short timeframe for data collection during 2 weeks in June 2023 means that some of the data may reflect the context during this time period. In addition, the views expressed were voluntary and represent the most recent experience of the client.
- The economic crisis adversely affected the availability of certain items and commodities that clients were seeking during the pilot data collection period.
- There were differing levels of participation across sites, with limited numbers of clients participating at Gampaha STD clinic and Colombo HIV clinic.
- The pilot only collected qualitative feedback from one site and important insights from other sites may have been missed.
- This was the first time of using a new toolkit and, even with training, local adaptation and extensive review and revision of the results, there may be issues with data quality.
- The scores are not representative of general patient care at the facilities profiled, at the individual level or overall, and only reflect the experience of the clients interviewed. CLM does not aim to measure the standard of care in the same way a rigorous population-based study, but is intended to be used for quality improvement.
- The data collection was completed through interview by a trained key population community representative.

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