



# COMMUNITY LED MONITORING IN MONGOLIA

Pilot Project Technical Brief

January 2024



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.<sup>1</sup> 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”.<sup>2</sup> 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<sup>3</sup> (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**



<sup>1</sup> 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>

<sup>2</sup> <https://healthequitymatters.org.au/wp-content/uploads/2022/08/SKPA2-CLM-Toolkit-2022.pdf>

<sup>3</sup> <https://www.ohchr.org/sites/default/files/Documents/Issues/ESCR/Health/RightToHealthWHOF2.pdf>

# METHODOLOGY

In Mongolia, a Technical Working Group (TWG) was established in April 2023 to provide oversight and coordinate the CLM pilot of HIV service delivery for key populations. The SKPA-2 CLM tools were translated into Khalkha Mongolian and data were collected through an online self-reported form on the website hosted by Youth for Health Centre, <http://clm.test4ub.org>, which was developed by a local IT consultant. The data collection phase for the pilot took place during May and June 2023. Data were collected on selected indicators (**Table 1**). More detailed information can be found in the pilot report<sup>4</sup> and the SKPA-2 CLM toolkit<sup>2</sup>.

## RESULTS

### A1: CLM participation.

A total of 205 individuals participated in the CLM pilot (105 men who have sex with men, 95 female sex workers, four transgender women and one transgender man) as shown in **Figure 2**. These individuals were clients of HIV and health services at 25 different clinics across the country. Most participants used three facilities – two CBO sites (Perfect Ladies and Youth for Health Center), which accounted for 45 and 61 participants respectively, and the government-run National Centre for Communicable Diseases (NCCD) clinic (34 participants). The remaining participants used 22 facilities ranging from provincial clinics to private facilities.

**Table 1. CLM Indicators**

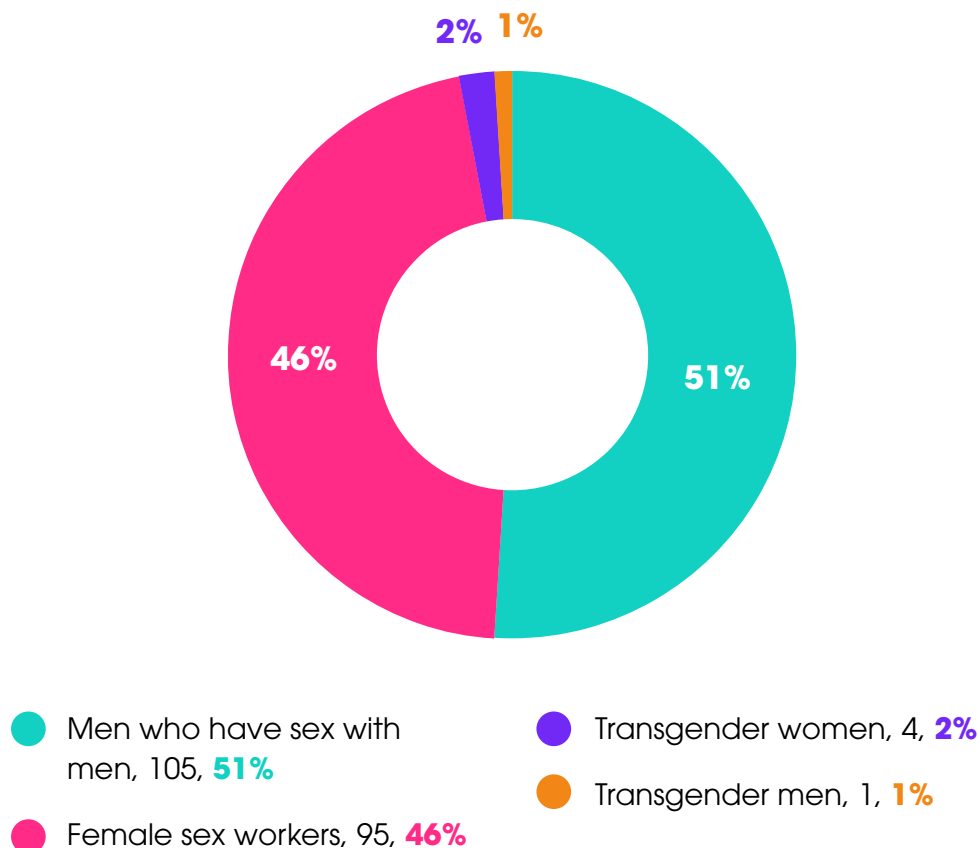
Indicator Short Name	Results
A1. CLM participation	205
A2. HIV service availability	96 %
A3. HIV service accessibility	79 %
A4. HIV service acceptability	77 %
A5. HIV service quality	66 %
A6. HIV service satisfaction	7
A7. Prevalence of serious incidents	-. <sup>*1</sup>
A8. Prevalence of stigma and discrimination	-
B1. Serious incident follow-up attempts	47.1 %
B2. Successful clients follow up of serious incidents	41.7 %
B3. Accurate reporting of serious incidents	0 %
B4. Referrals to services following a serious incident	N/A
B5. Successful and timely resolution of serious incidents	N/A

<sup>\*</sup>Due to data quality issues and accuracy of reporting, serious incidents are not reported for the pilot.

<sup>2</sup><https://healthequitymatters.org.au/wp-content/uploads/2022/08/SKPA2-CLM-Toolkit-2022.pdf>

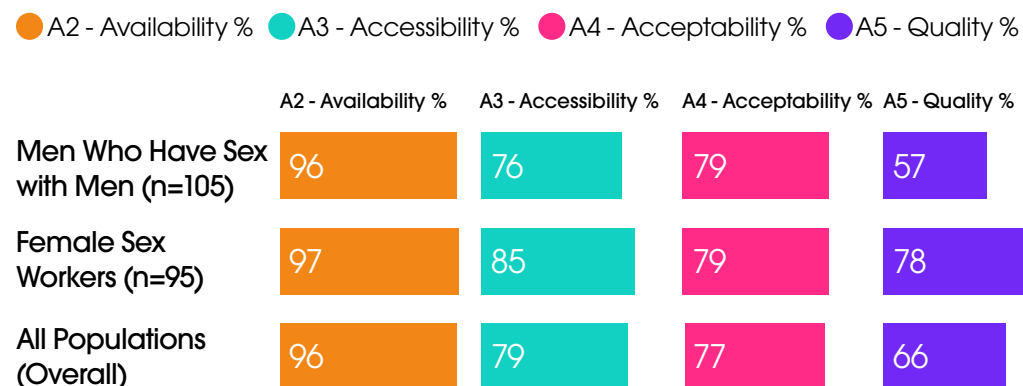
<sup>4</sup>Mongolia SKPA2 CLM Pilot Report, May-June 2023. Youth For Health Centre Mongolia

**Figure 2. CLM participants by key population group**



The pilot measured the **Availability, Accessibility, Acceptability** and **Quality** (AAAQ) of HIV services. The overall results are shown in **Figure 3**.

**Figure 3. Availability, Accessibility, Acceptability, and Quality Indicators by Key Population Group<sup>2</sup>**

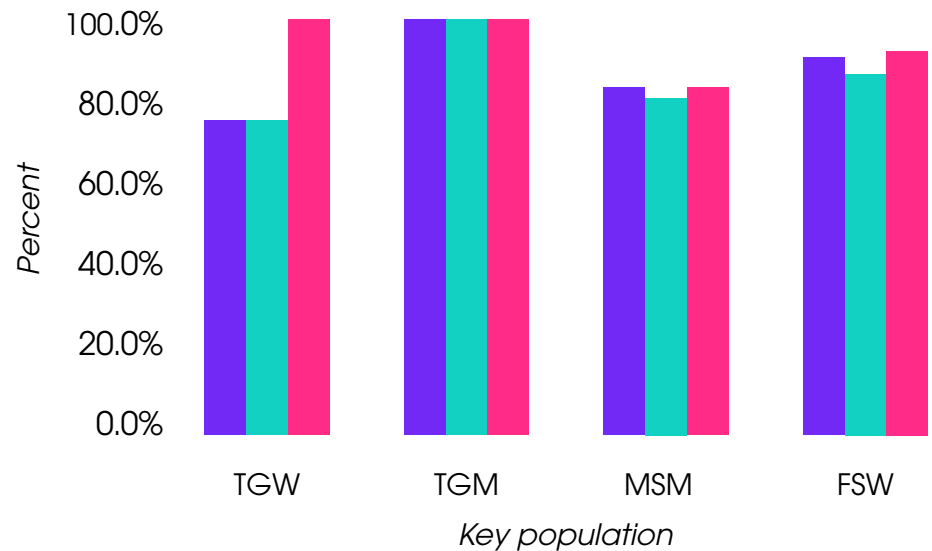


**A2. HIV Service Availability** was measured by taking both the number and percentage of users who received all of the HIV and health services that they sought. Availability of services was high with 96% of services sought received. Availability was higher than 90% for all services sought, ranging from a low of 91.7% for ART refills and 91.8% for STI services to 100% for ART initiation, post-exposure prophylaxis (PEP) and viral load testing. At facility level, there was consistently high access to HIV testing no matter the facility type, with 98% receiving HIV screening and 98% receiving confirmation HIV tests. Notably, availability of HIV counseling was lower at 94%, highlighting the need for improvement.

<sup>2</sup>Transgender women and transgender men are not included here as the sample size is small and pilot findings for the AAAQ indicators related to these key populations should be interpreted with caution.

**A3. HIV Service Accessibility** was measured using four different variables – convenient location, safe location, suitable opening hours, and affordable services – and all needed to be in place for the service to be rated as accessible. Overall, 79% of all key populations found HIV services to be accessible. With respect to the four variables, 88% of participants found the services to be both safe and convenient, 87% found them to be affordable and 84% found them to have suitable opening hours (84%). Findings were different for different types of facilities. Twenty participants accessed clinics other than those of the NCCD and key CBO partners and provincial clinics. These ‘other’ clinics scored lowest on accessibility, with only 60% of clients finding the opening hours convenient and 65% finding them affordable. Accessibility was highest at two CBO sites: Perfect Ladies (for female sex workers), where the lowest score for the variables was 98% for convenience of opening hours; and the Youth for Health Centre (for men who have sex with men), where convenience of opening hours was more of an issue (87% of participants found the hours convenient) than safety (92%) and affordability (93.4%). **Figure 4** provides an overview of the findings for the different variables for accessibility.

**Figure 4. Service Accessibility**



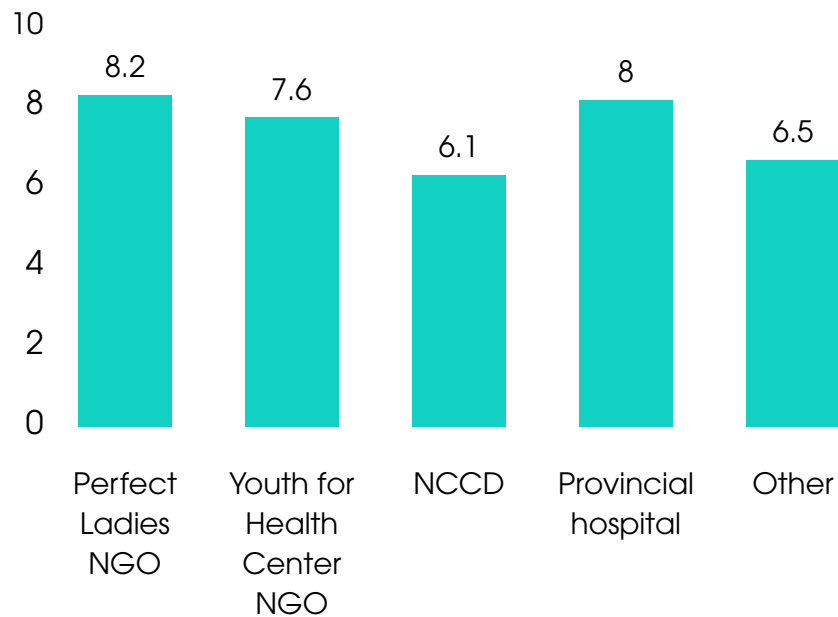
- Was the service affordable for you?
- Are the opening hours suitable for you?
- Was the HIV service location safe and convenient for you?

**A4. HIV Service Acceptability** was measured using three different variables – client treated respectfully, consent sought, and privacy and confidentiality met – and all three had to be in place for the service to be rated as acceptable. Overall, 77% of all key populations found services to be acceptable. Due to data quality issues (linked to translation of the privacy and confidentiality question), we have presented findings about acceptability based on the first two variables only. The proportion of all key populations who reported that their permission was sought for any procedure was very high at 92%, but there were differences between key populations. While 98% of female sex workers and 89% of men who have sex with men reported that consent was sought, only 50% of transgender women (two of four) reported this. Similar results were found for the other variable of interest, being treated respectfully, with only two of four transgender women reporting being treated respectfully, compared with 86.4% of female sex workers and 73.3% of men who have sex with men. Although the number of transgender women participating in the pilot was small, the findings suggest that there is a need for capacity building and trans-inclusive programming approaches to improve services for transgender women in Mongolia.

**A5. HIV Service Quality** was measured through three different variables – the client received all items or commodities they needed (e.g. medicines, condoms), the client did not have to wait ‘too long’ to see a healthcare provider, and the client received all the information they needed – and all had to be in place for quality of service. HIV service quality scored lowest out of the AAAQ indicators at 66% overall. Findings varied between variables and key populations. While, overall, 83% of participants received the commodities they needed, this ranged from 87.4% among female sex workers and 81% among men who have sex with men to 50% of transgender women. Similarly, a high proportion of female sex workers (93.7%) and men who have sex with men (89.5%) reported receiving all the information they needed, but the proportion was much lower among transgender women (50%). The main challenge to service quality was related to waiting time. Around a quarter of all participants reported that they experienced excessive waiting times, but the proportion differed between key populations. Only 12.6% of female sex workers had to face a long waiting time, compared with 30.5% of men who have sex with men, and 75% of transgender women.

**A6. Client Satisfaction** was rated on a scale from 1 to 10 and the pilot findings resulted in an average score of 7.3 and median score of 9. **Figure 5** illustrates the mean satisfaction results for the most frequented facilities. Perfect Ladies and the provincial hospitals (mostly use by female sex workers participating in the pilot) had the highest mean satisfaction with scores of 8.2 and 8 respectively. This is consistent with higher ratings in general among female sex worker participants for other indicators such as service quality. The higher satisfaction score for provincial hospitals also reflects participants reporting that they received the items and information they needed at these sites.

**Figure 5. Mean Satisfaction Score by Location**



### **A7-A8; B1-B5 Serious Incidents and Follow-up**

The pilot recorded slightly over 50 reports classified as serious incidents (indicator B1) and around half of these (47.1%) gave consent for follow up. Ten out of 24 (41.7%) were successfully followed up (indicator B2). Based on examination of these and their validity as per indicators B3 to B5, no actual serious incidents were identified. Given data quality issues, the pilot report does not include serious incident data for these indicators. The wording and translation of these questions will be assessed as part of the toolkit review process, to ensure consistent understanding among CLM participants in Mongolia.

# RECOMMENDATIONS

Based on the findings of the CLM pilot, we make the following recommendations for HIV service delivery for key populations and national CLM scale-up plans in Mongolia:

- Ensure the consistent availability of ART at clinics providing HIV services.
- Consider partnering other clinics with provincial hospitals, Youth for Health Centre, Perfect Ladies and other sites most frequently used by key populations, including formalized collaboration through Memoranda of Understanding, to share experience and learning in order to make services more key population-friendly.
- Develop quality improvement plans for clinics where there is room to improve the quality of HIV service delivery, with the involvement of relevant staff and partner clinics.
- Include healthcare professionals from participating clinics in human rights and gender training, strengthen confidentiality and privacy protection at clinics, and adapt clinic forms to integrate inclusive language, in order to foster a more welcoming environment for and increase the acceptability of HIV services to key populations.
- Seek to better understand the different experience of transgender people in HIV service accessibility, acceptability and quality and identify measures to address the specific barriers they face.
- Improve understanding of serious incidents among CLM participants through community outreach and simplified definitions.
- Revise the serious incident follow up policy to outline appropriate responses at different levels and track referrals, and support real-time monitoring of CLM data to ensure timely follow up of serious incidents.
- Establish a partnership with the National Legal Aid Center through a Memorandum of Understanding to provide legal support to individuals who have experienced serious incidents in healthcare settings and in the community, including all forms of violence.
- Increase awareness of and participation in CLM among key populations (in particular transgender populations) and service providers, and expand options to provide feedback on services.
- Expand the scope of CLM to include people living with HIV.
- Take steps to strengthen use of CLM findings to improve HIV service delivery, including through capacity building and hosting community forums to develop action plans and advocacy based on CLM data.
- Investigate opportunities for integrated CLM across disease areas including TB to minimize duplication and improve the efficiency of data collection and data for decision-making.

During the pilot, participants were also given the chance to provide open-ended feedback. Specific requests, in addition to the recommendations listed above, included: extending facility opening hours including offering weekend services; providing specific services including PrEP and contraceptives; offering face-to-face counseling and telephone consultations; reducing bureaucracy involved in accessing services; and providing assistance to people with disabilities.

Following the dissemination of the findings from the pilot, Mongolia is now improving the CLM tools and providing training and advocacy support for service providers and key population communities. Memoranda of Understanding are being established with facilities that serve the highest numbers of key population clients.



# CONCLUSION

The CLM pilot was successful in testing data collection, analysis and report writing and showed that the overall framework and process were feasible. It also showed that the toolkit needed to be adapted to suit the local context together with ensuring that the tools are field tested and understood by community members. As the first exercise with a new toolkit, there were data quality gaps and, even with training, local adaptation and extensive review and revision of the results, there remained several unknowns around data quality. The pilot also identified the need to build a stronger culture of using data for decision making and, more specifically, to build capacity for effective use of CLM findings to advocate for policy change and improvements in service delivery and quality.

The pilot findings highlight differences between key populations in reported experience of using HIV services and the need to understand specific access barriers faced by different key populations and to consider specific solutions, rather than taking a one-size-fits-all approach. Although the sample was small, transgender women were less likely to report that they were treated respectfully by staff, that staff sought their consent for procedures, that they didn't have to wait too long for the service or that they received the STI services they sought. Transgender women were identified as having elevated HIV prevalence in the latest national HIV surveillance studies and expanding coverage of CLM for this group and acting on their feedback on HIV service quality will be important to ensure that this priority population remains engaged in HIV prevention and treatment. There is also room for improvement of specific services. For example, 14% of men who have sex with men reported not receiving the ART refills they were seeking, so efforts are needed to ensure ART is consistently available to clients.

It is difficult to interpret the lack of serious incidents identified in the pilot. Although there were data quality issues related to the reported incidents that were followed up, other factors, including improving community understanding of the follow-up process and awareness of clients' rights, will also need to be addressed as part of CLM scale-up.

A serious incident follow-up protocol was developed in 2023 and reviewed by the CLM TWG and technical assistance providers in the region. As a result of the pilot and further review, additional recommendations have been outlined and the protocol will be revised in early 2024 with plans to begin referrals in quarter two of 2024. A CLM dashboard is currently available in attesting phase (<https://clm.test4ub.org/statistic.php>). CLM indicators are now integrated in the National Monitoring and Evaluation framework as part of the Extended Action Plan (EAP), which is the Mongolian equivalent of a National Strategic Framework. The integration of CLM indicators into national policy will ensure sustainability and strengthen buy-in among national stakeholders beyond the life of SKPA-2.

## CONSIDERATIONS

- The scores presented are not representative of general patient care at the facilities profiled, at the individual level or overall, and are only related to the person's interviewed and the specific visit. The views expressed by participants were obtained voluntarily and represent their most recent experience of using HIV services.
- CLM is a non-research programmatic activity. The data as well as the insights presented are intended for quality improvement purposes and may not reflect or measure the standard of care in the same way as a more rigorous population-based study.
- 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.

## REFERENCES

<sup>1</sup> 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>

<sup>2</sup> <https://healthequitymatters.org.au/wp-content/uploads/2022/08/SKPA2-CLM-Toolkit-2022.pdf>

<sup>3</sup> <https://www.ohchr.org/sites/default/files/Documents/Issues/ESCR/Health/RightToHealthWHOF2.pdf>

<sup>4</sup> Mongolia SKPA2 CLM Pilot Report, May-June 2023. Youth For Health Centre Mongolia

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# THANK YOU

[healthequitymatters.org.au](http://healthequitymatters.org.au)

For further information,

please contact

**Ms. Felicity Young**

**Principal Director - SKPA-2**

[felicity.young@healthequitymatters.org.au](mailto:felicity.young@healthequitymatters.org.au)