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SUSTAINABLE COMMUNITY-LED MONITORING OF HIV SERVICES

A Toolkit for Key Populations | June 2022

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Foreword and acknowledgements

This toolkit presents a simple approach to measuring the quality of HIV services for key populations from the perspective of service users through Community-Led Monitoring[1] (CLM). Developed by the Australian Federation of AIDS Organizations (AFAO) and its partners under the first *Sustainability of HIV Services for Key Populations in Asia (SKPA)* program, which is funded by the Global Fund, it complements existing guidance on CLM (see resources on page 25).

In addition to providing an overview of planning and implementing CLM, the toolkit aims to strengthen CLM through the use of well-defined indicators that are linked to an internationally accepted service quality framework, and can be collected and analyzed by community members. It also addresses the link between service feedback and resulting action, through the introduction of a new follow-up form – and related indicators – for incidents that require investigation. As CLM can take different forms in different country settings, the toolkit avoids being prescriptive about 'how to' implement CLM and focuses on presenting a process and general considerations for each stage of this process.

The toolkit was developed towards the end of the first SKPA program and was informed by the experience of many partners in implementing the first round of work known as community-based monitoring. This toolkit has built upon this strong foundation and will take the work further under SKPA-2. AFAO would like to express its gratitude to the Asia-Pacific Coalition on Male Sexual Health (APCOM), the Asia-Pacific Transgender Network (APTN), the Asia-Pacific Network of People living with HIV (APN+), the Asia-Pacific Network of Sex Workers, and the Philippine NGO Pinoy +. For their leadership in this area. AFAO would also like to thank the following SKPA-1 subrecipients: Save the Children Bhutan, the Family Planning Association in Sri Lanka, the Community Health and Inclusion Association in the Lao People's Democratic Republic, Youth for Health Center in Mongolia, Burnet Institute in Papua New Guinea, Love Yourself in the Philippines, Estrella+ in Timor-Leste, and the Malaysian AIDS Council. We also thank the United Nations Joint Program on HIV/AIDS (UNAIDS) and the Global Fund for their significant contributions.

We hope the toolkit will prove useful to key populations and all stakeholders working on CLM.

1. Also known as Community-Based Monitoring (CBM). To be consistent with other recent publications and resources, Community-Led Monitoring (CLM) is used throughout this document.

Acronyms and Abbreviations

AAAQ	Availability, accessibility, acceptability, and quality
AFAO	Australian Federation of AIDS Organizations
APCOM	Asia-Pacific Coalition on Male Sexual Health
APN+	Asia-Pacific Network of People Living with HIV
APTN	Asia-Pacific Transgender Network
ART	Antiretroviral therapy
CBM	Community-based monitoring
CBO	Community-based organization
CLM	Community-led monitoring
DHIS-2	District Health Information System Version 2
HIV	Human immunodeficiency virus
HIVST	HIV self-testing
LTFU	Lost to follow-up
M&E	Monitoring and evaluation
MMD	Multi-month dispensing
MoH	Ministry of Health
NGO	Non-governmental organization
OST	Opioid substitution therapy
PEP	Post-exposure prophylaxis
PEPFAR	United States President's Emergency Fund for AIDS Relief
PrEP	Pre-exposure prophylaxis
QI	Quality improvement
QR	Quick response (QR) code
SKPA	Sustainability of HIV Services for Key Populations in Asia
STI	Sexually transmitted infection
TB	Tuberculosis
TWG	Technical Working Group
UIC	Unique Identifier Code
UNAIDS	Joint United Nations Program on HIV and AIDS

CONTENTS

How is the toolkit organized?

This toolkit includes four sections:

1 WHAT IS CLM AND WHAT CAN CLM MONITOR?

This section includes a definition of CLM, a framework for CLM monitoring and evaluation (M&E), a framework for assessing HIV service quality using CLM and related indicators and tools.

2 WHAT ISSUES NEED TO BE CONSIDERED IN CLM PLANNING?

This section covers who to involve in CLM, where CLM takes place and ethical considerations.

3 WHAT ISSUES NEED TO BE CONSIDERED IN CLM IMPLEMENTATION?

This section describes the process of CLM and different methods for data collection, as well as how to package and report the data collected.

4 HOW TO USE CLM FINDINGS TO IMPROVE HIV SERVICES?

This section focuses on the role of partnerships, dialogue and advocacy in making good use of CLM data to improve HIV services.

1

WHAT IS COMMUNITY-LED MONITORING AND WHAT CAN IT MONITOR?

What is CLM and why is it important?

CLM is an important aspect of community engagement in HIV program delivery. It involves activities that are carried out by community-based or community-led key population organizations and community members to assess the quality, availability, accessibility and acceptability of the HIV services they receive. Although there are different definitions of CLM, they all share the following principles:

- CLM aims to collect and use information to advocate for improvements in HIV services for key populations.
- CLM is owned and led by communities and community-led organizations and communities decide what to monitor and how to use the data collected.

CLM shifts the dynamic from HIV service providers monitoring service quality to monitoring that is led by the people who use HIV services

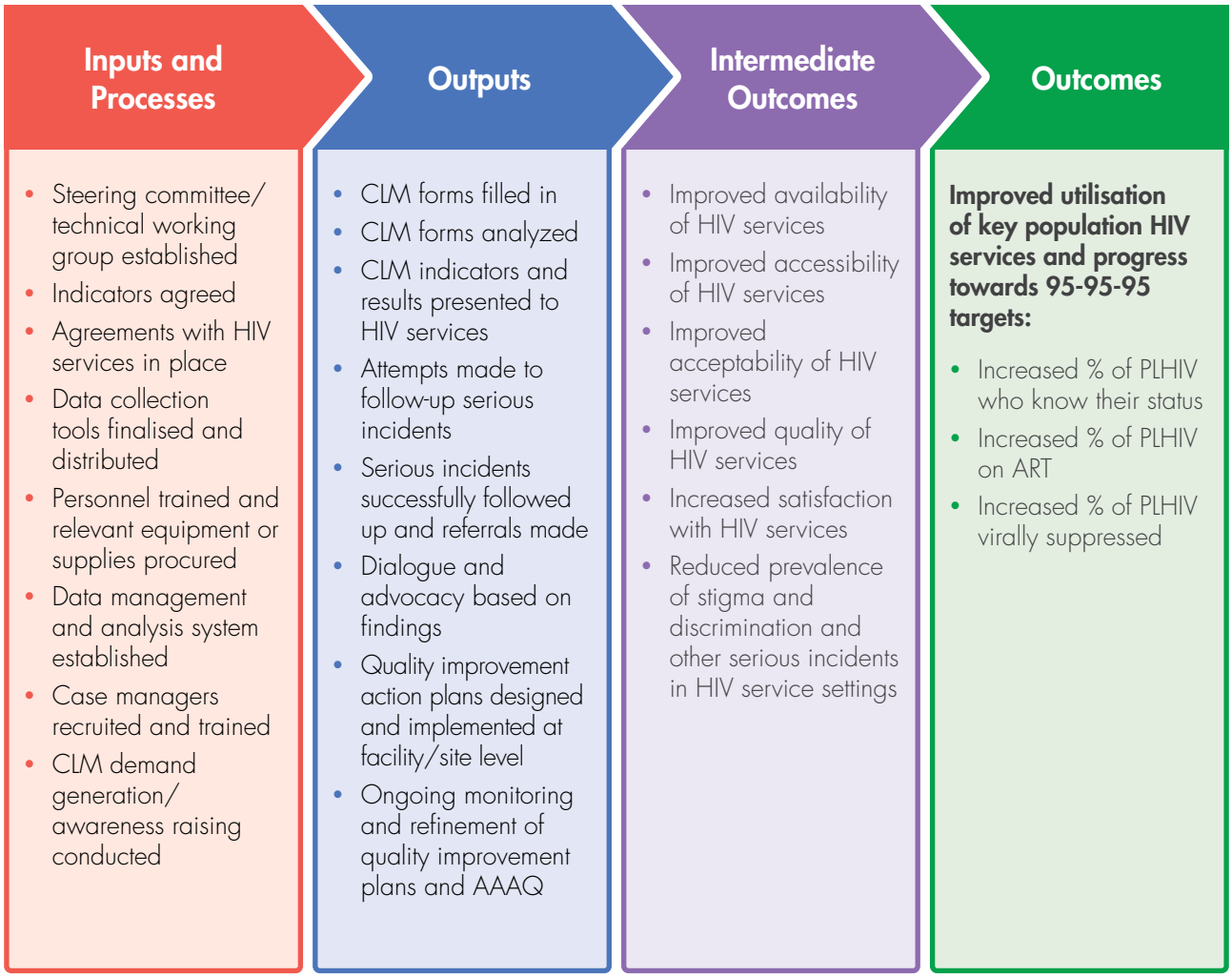
This toolkit uses an adapted version of the Global Fund definition of CLM:[2]

Community-led monitoring is 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. The Global Fund (May 2020) Community based monitoring: An overview; https://www.theglobalfund.org/media/9622/core_css_overview_en.pdf. Accessed on September 20, 2021.

Improvements in HIV services for key populations are expected to increase uptake of and retention in HIV services, leading to improvements in health and life expectancy. By improving uptake of and retention in HIV services, CLM can also help countries to achieve their 95-95-95 targets. Figure 1 uses a 'logical framework' to show how CLM can contribute to this. A logical framework is a tool that is used to describe how programs or activities are expected to contribute to desired results and to monitor and evaluate program progress towards these results.

Figure 1. M&E Logical Framework for CLM



How can CLM measure the quality of HIV services?

The logical framework (Figure 1.) shows how CLM activities can contribute to improved HIV program outcomes and help meet national targets. One of the critical assumptions in the logical framework is that CLM can lead to improvements in HIV service quality, so we now need to turn our attention to how 'quality' will be measured. There are different definitions of service quality. This toolkit uses an adapted version of a framework for assessing health services that has four interconnected dimensions: availability; accessibility; acceptability; and quality. The Availability, Accessibility, Acceptability, Quality (AAAQ) framework is used in many countries to assess different types of services for different populations. The adapted version of the framework shown in Figure 2 is a useful basis for assessing the factors that affect the availability, accessibility, acceptability and quality of HIV services for key populations.

Figure 2. Adapted AAAQ framework for the CLM toolkit

The AAAQ framework can also be linked to the logical framework above. For example, data collected on the availability, accessibility, acceptability and quality of HIV services is one of the key outputs of CLM in the logical framework, and improvements in service availability, accessibility, acceptability and quality are key outcomes of CLM.

In this toolkit, the definitions of availability, accessibility, acceptability and quality have been adapted to reflect the comprehensive package of HIV services for key populations and specific issues that are important for key population service users.

AVAILABILITY refers to the existence of some or all of the following services:

a. Prevention:
   - Provision of condoms and lubricants
   - HIV testing (including facility-based testing, HIV self-testing and community-based testing)
   - Pre- and post-test counseling
   - STI diagnosis and treatment
   - PEP
   - PrEP

b. Care and treatment:
   - Case management (including enrolment, adherence and retention support)
   - ART early initiation
   - ART refill/follow-up/multi-month dispensing
   - ART restart after discontinuation
   - ART counseling (including benefits, adherence, side effects, viral load monitoring)
   - Viral load monitoring
   - TB diagnosis and treatment
   - Referral and linkage to other services (including nutrition, mental health, social welfare, legal support)

c. Key population-specific services:[3]
   - Harm reduction services for people who use drugs (opioid substitution therapy, needle and syringe exchange)
   - Transgender-specific health care (counseling, gender-affirmative treatment)
   - Violence prevention services for sex workers
   - Reproductive health services for young people and sex workers

3. These services are not included on the client form introduced here, but could be added, depending on program or country context

ACCESSIBILITY refers to some or all of the following issues:

- Physical accessibility (whether the health facility is easy to reach/not too far)
- Opening times (whether opening days and hours are convenient/appropriate)
- Safety of the facility environment
- Financial accessibility (whether services are affordable)
- Administrative accessibility (whether it is easy to register and use the service or there are bureaucratic processes that prevent access)
- Awareness of services (incuding whether services are free, key population-friendly, anonymous)

ACCEPTABILITY refers to how culturally and socially acceptable health services are to users, based on some or all of the following issues:

- Confidentiality and privacy of personal information
- Informed consent (whether informed consent is requested prior to receiving services)
- Equity and respect for all service users, gender diversity and sexual diversity (the extent to which all service users are treated equally, irrespective of culture, gender, sexual orientation, age, religion, and made to feel equally welcome, and use of appropriate pronouns by health care providers)
- Stigma and discrimination (whether the health facility and staff are free from stigma and discrimination)

QUALITY refers to the user's perception of service quality, based on some or all of the following issues:

- Staff knowledge and skills (the extent to which service users view staff as professional, qualified, confident, able to answer questions and provide options/alternatives)
- Supplies (whether there is adequate supply of high-quality medicines, condoms, lubricants, other commodities)
- Client-centerd approach (whether the facility and staff give service users clearly explained options and act on what clients need)
- Timing (whether there are no long waiting times)
- Referral (ease of the referral process)

What indicators and data collection tools can you use for CLM?

Indicators are the specific measures that are used to assess services in CLM and, therefore, are the focus of data collection. Table 1 includes a list of the indicators that are likely to be most important in CLM. The list includes two types of these 'core' indicators': those that provide information about the experience and perception of service users (A. Key population CLM indicators in Table 1); and those that relate specifically to follow-up of reports of "serious incidents" related to human rights, patient safety or confidentiality violations (B. Key population CLM serious incident follow-up indicators in Table 1). It is important to only collect data for indicators that are relevant and useful, and to adapt core indicators and terminology if necessary so that they are appropriate to the country context.

This toolkit includes two tools for data collection: a CLM key population client form (see Annex 1), which collects data on the experience and perceptions of service users; and a CLM client follow-up form (see Annex 2), which collects data on follow-up of serious incidents.

Table 1. Core CLM Indicators

Indicator number	Indicator short name	Indicator long name	What the indicator tells us	Definition/computation[4]
		A. Key population CLM Indicator		
A1.	CLM participation	Number of key population CLM client forms received	A measure of key population participation in CLM within a certain period of time. A high number of CLM client forms received indicates high levels of participation in CLM (the total key population size would be needed to use this data to assess coverage or the proportion who are participating). Analyzing this by risk behaviour (Q22), gender (Q21) and age (Q20) will provide more detailed information about who is participating in CLM.	The number of CLM forms received from key population HIV service users within a certain period of time (e.g. month, quarter) where a defined HIV service was received, or sought but not received, indicated by a 'yes' or 'no' box checked next to any service in Q5, Section 2 of the CLM client form.
A2.	HIV service availability	Number and percentage of HIV service visits where the services were rated as available	A measure of whether key populations are able to successfully receive the HIV service(s) they are seeking. 'Availability' here only covers whether or not the service key population clients sought was received. High levels of unmet demand could be used to advocate for the expansion of certain services.	Numerator: The number of CLM forms filled in by key populations where there is a 'yes' checked next to every service sought (in the 'did you receive it' column) on the client form (Q5a-Q5n) Section 2[5]

4. For indicators where "number and percentage" is indicated, the number is the same as the numerator in the definition column. The percentage is calculated by dividing the numerator by the denominator.
5. It will be important to analyze HIV service availability based on the specific service clients are seeking, e.g. contrast the availability of HIV testing services (5a.) compared to anti-retroviral therapy initiation (5h.)

Indicator number	Indicator short name	Indicator long name	What the indicator tells us	Definition/computation[4]
A2. cont.				Denominator: The number of CLM forms filled in with one or more boxes checked under the service sought column (Q5a-Q5n) Section 2
A3.	HIV service accessibility	Number and percentage of HIV service visits where the services were rated as accessible	A measure of how safe, affordable and convenient it is for key populations to access the HIV services they are seeking. Accessibility here covers (1) safety and convenience of the location, (2) suitability of opening hours and (3) affordability of the service(s). ALL conditions need to be met to rate the service visit as accessible. High percentages indicate that key populations overall view the HIV services they use as accessible. Further analysis is encouraged including constructing indicators for each of these three criteria individually so the analysis can help identify specific access barrier(s).[6]	Numerator: The number of CLM forms filled in by key populations where there is a 'yes' checked next to every accessibility-related question on the client form (Q6-8). Denominator: The number of CLM forms filled in with an entry in the yes or no column for every accessibility-related question on the client form (Q6-8).
A4.	HIV service acceptability	Number and percentage of HIV service visits where the services were rated as acceptable	A measure of how acceptable key populations found the HIV service they received. Acceptability here covers: (1) perception that the client was treated respectfully by staff at the facility, (2) whether their consent was sought for any procedures and (3) privacy and confidentiality. ALL conditions need to be met to rate the service visit as acceptable. High percentages indicate that key populations tend to view the HIV service they use as acceptable. Further analysis may be helpful (see A3 above and footnote 5 below).	Numerator: The number of CLM forms filled in by key populations where there is a 'yes' checked next to every acceptability-related question on the client form (Q9 and Q10) and a 'no' checked for breach of privacy or confidentiality (Q15d). Denominator: The number of CLM forms filled in with an entry in the yes or no column for every acceptability-related question on the client form (Q9, 10 and 15d)

6. This will help pinpoint specific barrier(s) to quality services, such as affordability or inconvenient opening times, rather than just concluding services are not 'accessible' or 'acceptable'.

Indicator number	Indicator short name	Indicator long name	What the indicator tells us	Definition/computation[4]
A5.	HIV service quality	Number and percentage of HIV service visits where the services were rated as good quality	A measure of the quality of the HIV service key populations received. Quality here covers: (1) whether the client received items or commodities they needed (e.g. medicine, condoms, information, lubricants), (2) whether they had to wait too long to see the health care provider[7] and (3) whether they received all the information they needed and had their questions answered. ALL conditions need to be met to rate the service as good quality. High percentages indicate that key populations tend to view the HIV service they use as good quality. Further analysis may be helpful (see A3 and footnote 5 above).	Numerator: The number of CLM forms filled in by key populations where there is a 'yes' checked next to every quality-related question on the client form (Q11, 12 and 13). Denominator: The number of CLM forms filled in with an entry in the yes or no column for every quality-related question on the client form (Q11, 12 and 13)
A6.	HIV service satisfaction	Mean (average) overall satisfaction score	A measure of overall satisfaction with the service through a score of between 1 and 10. A high score indicates a high level of general satisfaction and willingness to refer peers to the service. A low score indicates a low level of satisfaction.	The mean (average) of scores on all CLM client forms entered in Q14
A7.	Prevalence of serious incidents	Number and percentage of key population service visits where a serious incident is reported[8]	A measure of the prevalence of "serious incidents" (e.g. human rights violations such as breach of confidentiality, stigma and discrimination, violence or sexual harassment) reported by key population HIV service users. This indicator will be disaggregated by the type of serious incident, namely: • Stigma and discrimination • Violence • Sexual harassment • Breach of confidentiality or privacy • Refused service because of gender, race, identity, risk behaviour, or other • Pain or distress	Numerator: The number of CLM forms filled in by key populations where there is a 'yes' checked next to one or more of the serious incident pre-defined categories on the client form (Q15, a-g). Denominator: The number of CLM forms received from key population HIV service recipients within a certain period of time (e.g. month, quarter) where a defined HIV service was received (Q5a-5n) as indicated

7. "Too long" waiting time is subjective, and the perception of how long is "too long" to wait can vary significantly from client to client. Community organizations may choose to replace this with a time limit (e.g. 1 hour) based on service standards.
8. Care must be taken in interpreting a high percentage of serious incidents, particularly when making comparisons across facilities or other geographic units. It may be that in some areas key populations are more likely to fill the form in only when they experience a serious incident, while in others they are more likely to provide general feedback. This may be related to how the CLM tools are introduced. A consistent approach to introducing CLM tools within a country will help make these comparisons more meaningful. The same consideration applies to indicator A8.

Indicator number	Indicator short name	Indicator long name	What the indicator tells us	Definition/computation[4]
A7. cont.			Any serious incident report needs to be followed up with the client, and potentially the service provider/manager.[9]	through a 'yes' box being checked in Q5 on the client form.
A8.	Prevalence of stigma and discrimination	Number and percentage of key population HIV service visits where stigma and discrimination was reported	A measure of the prevalence of stigma and discrimination reported by key population HIV service users. This is a subset of indicator A7 *the number of visits where a serious incident is reported*. Any stigma and discrimination incident needs to be followed up with the client, and potentially the service provider/manager.	Numerator: The number of CLM forms filled in by key populations where there is a 'yes' checked next to stigma and discrimination in the serious incident section of the client form (Q15a.). Denominator: The number of CLM forms received from key population HIV service recipients within a certain period of time (e.g. month, quarter) where a defined HIV service was received (Q5a-5n) as indicated through a 'yes' box being checked in section 2 on the client form.
B. Key population CLM serious incident follow-up indicators				
B1.	Serious incident follow-up attempts	Number and percentage of serious incident reports followed up	A measure of efforts to follow-up serious incidents. This is the number and percentage of CLM follow-up forms where at least one attempt has been made to reach the client.	Numerator: The number of CLM follow-up forms filled in with one or more attempts made to contact the client (a 'yes' or 'no' checked in Q14 on the follow-up form). Denominator: The number of CLM client forms filled in with one or more serious incidents indicated (Q15a-g) .[10]
B2.	Successful client follow-up of serious incidents	Number and percentage of serious incident reports where a successful contact	A measure of successful follow-up of serious incidents. The numerator measures the number of serious incidents with a successful follow-up attempt, while the percentage measures the relative success in contacting clients to review the incident and plan follow-up	Numerator: The number of CLM follow-up forms where the individual making the follow-up attempt successfully contacted the key population HIV service

9. The list of serious incidents included in the data collection tool can be edited following country level stakeholder consultation. 'Adverse events' can also be used as an alternative to 'serious incidents'.
10. An alternative source of data for this denominator is section 3 (Q15) on the follow-up form – only if the data is consistently transferred from Q15 on the client form to here.

Indicator number	Indicator short name	Indicator long name	What the indicator tells us	Definition/computation[4]
B2. cont.		with a key population HIV service client was made for follow-up	actions. A low percentage could highlight a lack of useful contact details on the follow-up forms, low intensity of follow-up efforts, or both.	user reporting a serious incident (a 'yes' checked in Q14 of the follow-up form) Denominator: The number of CLM follow-up forms with a serious incident indicated and one or more attempts were made to contact the client (a 'yes' or 'no' checked in Q14 on the follow-up form)
B3.	Accurate reporting of serious incidents	Number and percentage of serious incidents correctly recorded	A measure of accurate reporting of serious incidents on the CLM client form. This is generated during the client follow-up process where the case manager or HIV service supervisor[11] conducting follow-up will discuss the nature of the 'serious incident' with the client in a confidential and supportive manner. The case manager will then use their best judgement (based on relevant national guidelines) to determine whether the incident was correctly categorized and reported on the form. This is a data validation process, while also forming an important part of client follow-up and case management.	Numerator: The number of CLM follow-up forms with a 'yes' next to Q16 on the follow-up form ('was this a serious incident?'). Denominator: The number of CLM follow-up forms with a 'yes' OR 'no' next to Q16 on the follow-up form ('was this a serious incident?').
B4.	Referrals to services following a serious incident	Number and percentage of serious incidents referred to services	A measure of case management of serious incidents. Following the validation of a serious incident by case managers (see B3.) referrals to follow-up services may be needed. These follow-up services include: (1) HIV/health services, (2) counseling services, (3) legal services, (4) social welfare services and (5) other.[12]	Numerator: The number of CLM follow-up forms with the 'yes' box ticked under one or more of the services listed in Q17 referrals (Q17a-e). Denominator: The number of CLM follow-up forms with a 'yes' next to Q16 on the follow-up form ('was this a serious incident?').

11. A case manager could be an outreach worker, counsellor, or other trained CBO staff/volunteer tasked with following up CLM serious incident reports. It could also be an independent staff member of the health facility (someone other than the HIV service provider who served the client) or a member of a district or local government health team.
12. Case managers need information about referral services before they speak to the client - including alternate HIV or health services, counseling services, social welfare, legal and other relevant services.

Indicator number	Indicator short name	Indicator long name	What the indicator tells us	Definition/computation[4]
B5.	Successful and timely resolution of serious incidents	Number and percentage of serious incidents resolved within 30 days[13]	A measure of the successful resolution of serious incidents in a timely manner.	Numerator: The number of serious incidents successfully resolved within 30 days — from reporting the incident (Q18b). The time taken to resolve the incident can be calculated by counting the number of days in between Q4 (date of the CLM report) and Q5 (date of this follow-up) on the client follow-up form. Denominator: The number of CLM follow-up forms with a 'yes' next to Q16 on the follow-up form ('was this a serious incident?').

As Table 1 shows, core CLM Indicators fall into two categories:

A **Key population CLM indicators:** There are eight indicators, including one for CLM participation (A1), five linked to the AAAQ client satisfaction framework (A2-A6), and two for reporting serious incidents (A7 and A8). Data for these indicators is collected using the CLM client form (Annex 1) which has five sections: 1) HIV/health service details and visit date; 2) feedback on the service (the AAAQ indicators); 3) reports of any serious incidents experienced;[14] 4) client profile; and 5) general feedback and follow-up. Sections 1 and 4 provide information about the health facility visited and the client, to allow more detailed analysis.There are 26 questions all together and the form should take around 10 minutes to complete.

B **Key population CLM serious incident follow-up indicators:** There are five indicators, including two indicators that measure serious incident follow-up efforts (B1 and B2), one indicator related to data quality, which validates the reporting of serious incidents (B3[15]) and two indicators related to case management of serious incidents (B4 and B5). Data for these indicators is collected using the CLM client follow-up form (Annex 2), which is filled in by the person responsible for follow-up of serious incidents (e.g. case managers, HIV service supervisors). This form has five sections: 1) follow-up details; 2) follow-up attempts; 3) recap of serious incident(s) to be followed up; 4) information following successful contact with the client; and 5) final result from this follow-up attempt. The form documents both successful and unsuccessful follow-up attempts; a new form should be filled in for each follow-up attempt.

13. 30 days is used as a benchmark for timely resolution of serious incidents, recognizing that complex cases (e.g. those involving the legal system) may take longer to resolve. Analysis by type of serious incident will help identify those that can usually be resolved in a timely manner. An indicator for successful resolution of serious incidents can also be constructed from 18b, by ignoring the time taken to resolve the incident
14. Serious incidents have been categorized as including: 1) stigma and discrimination; 2) experiences of violence linked to receiving the service; 3) experiences of sexual harassment from service staff or other clients; 4) breach of privacy or confidentiality regarding the client's personal information; 5) refusal of service because of gender, identity, race, risk behaviour or other; and 6) experience of pain or distress. There is the option to include other serious incidents not covered by these categories and the list can be tailored to country contexts.
15. This question can be used to correct the number and type of serious incidents reported through CLM, and case managers should be guided by a standard operating procedure on how to review and validate the incident in discussions with the client, and what referrals to make, depending on the incident.

2

WHAT ISSUES NEED TO BE CONSIDERED IN CLM PLANNING?

Populations and eligibility criteria

Any member of a key population using HIV services should be eligible to participate in CLM. This includes people living with HIV, men who have sex with men, transgender women and men, sex workers and people who use drugs.

On the CLM client form, the category of key population can be identified through answers to questions about risk behaviour Q22a-e. If none of the boxes from 22a. to 22e. are checked, we cannot be sure the feedback is from a key population. In principle it is better to exclude feedback from non-key populations in the analysis, but it is important to remember that some people may prefer not to disclose their behaviours or identify as a member of a key population when they fill in the feedback form. One option is to analyze this feedback (from individuals who do not identify as key populations) separately as it may provide useful data for service quality improvement.

CLM data is most useful if it is collected from key populations who have recently used HIV services (e.g. in the last month). This helps to reduce the risk of recall bias and the chance of identifying issues that have already been corrected.

Facilities and sites

To ensure that CLM improves services, it is important to link the feedback data collected to the facility where the service was delivered and the date it was delivered. This allows the facility or HIV service manager to follow-up any issues with the health care provider(s) who were on duty at the time. The name and location of the facility are entered in section 1 of the CLM client form, and in section 1 of the CLM client follow-up form. A facility can be a public, private or community-based site where key populations seek HIV prevention, testing or treatment services, but only facilities that have formally agreed to be part of the CLM system should be included.

Number of service visits vs. number of service users

Each CLM client form refers to a single visit to a HIV service, so the denominator for most indicators is the number of service visits within a specific period of time. This is different to the number of service users, as an individual may make several visits and fill in several CLM client forms, during the same timeframe.

It is possible to calculate the number of individuals receiving services and participating in CLM from the CLM client forms if a unique identifier code (UIC) is used for each client (Q23 on the CLM client form). Some countries have UIC systems that are standardized at national level, however UICs are not always easy for clients to remember when they are filling in a CLM form. Another means of distinguishing individuals from visits is question 19 on the client form. If a client indicates they are providing feedback for the first time ever, or the first time within the last 12 months, an estimate of the number of individuals participating in CLM ever, and during the year, is possible.

Individual level analysis may also be possible if the UIC field is filled or auto-generated through an electronic follow-up system linked to client service bookings. Such electronic systems make it possible to differentiate individuals from visits, and can increase the coverage of CLM by automatically distributing the client form through an electronic platform right after the service visit.

Because of challenges associated with UICs in many contexts, the service visit rather than the service user is the recommended unit of analysis for CLM. In addition, as CLM seeks to improve the quality of services provided by facilities, feedback from every service visit is important and every visit is different.

Ethical considerations

Although CLM is a program activity and not research, ethical approval will be required in some countries, as key populations include vulnerable individuals. The need for ethical review board approval for CLM should be discussed early with government and other national stakeholders. Regardless of whether approval is required, the following ethical principles should apply to all CLM activities:

Voluntary participation: Individuals participating in CLM must do so without coercion. They should be able to withdraw their participation at any time, without the need to give a reason. Their right to receive services from a health facility or national program should not be related in any way to their participation or non-participation in CLM activities.

Informed consent: Before they participate in CLM, individuals should be fully informed about the activity. Fully informed means that they understand the objectives of CLM, they are aware of the source of funding, national and/or local approvals, they know how much time their participation will involve, how the findings will be used, the risks and benefits of participation, and are aware that they may be contacted for follow-up. Only then can they make an informed decision about whether or not to participate, and either provide their consent or decide not to participate, without any penalty or negative consequence.

Confidentiality: Any identifying information should not be made available to anyone except with the express consent of the participants. Identifying information, such as telephone numbers in the case of serious incident reporting, must be stored securely and only used for service follow-up and referral purposes.

Anonymity: The anonymity of individuals participating in CLM must be protected. The data collection forms should not collect the names or addresses of participants. The only identifier that participants should be asked for is a first name or nick name, telephone number, email address or social media username, so they can be contacted if there is a need to follow-up a serious incident.

Privacy: The privacy of individuals participating in CLM is also important. All data collected during CLM should be managed in a way that protects the privacy of participants (visual and auditory privacy) and the confidentiality of the information they provide, so that feedback cannot be linked to the individual who provided it.

Do no harm: Everything should be done to ensure that individuals involved in CLM are protected from psychological or physical harm that could result from their participation.

These ethical principles should be covered in training for those who will be involved in CLM in any way, including data collection, management and analysis. A sample code of conduct for individuals participating in CLM is in Annex 5.

3

WHAT ISSUES NEED TO BE CONSIDERED IN CLM IMPLEMENTATION?

The CLM Process

The CLM process is a cycle with six interconnected stages (see Figure 3). Each stage in the cycle is described below.

Figure 3: The CLM Process

1 Establish partnerships with other community partners

- Identify a lead organization for CLM implementation. Often this is an organization that is trusted by key populations and has funding and staff available, but it important that this organization is not involved in service delivery at facilities where CLM will be conducted, to avoid a conflict of interest and bias in CLM findings. See also Box 2.
- The lead organization needs to establish strong partnerships with other community-based organizations and groups involved in HIV service delivery to make sure that CLM is owned by communities and covers all key populations and the full range of HIV services, to ensure that CLM is not 'monopolized' by one organization.
- After CLM is established, there may be opportunities for CLM models that do not rely on a lead organization, with anonymous or aggregate data uploaded and stored on an open-source database where all partners and stakeholders can access and interact with it.

Box 1: Establishing partnerships for sustainability of community-led monitoring in Bhutan

In 2020, a partnership of organizations including key population-led organizations (Pride and Lakh-Sam Bhutan) and an international non-governmental organization (Save the Children Bhutan) implemented the first phase of CLM activities in Bhutan under the Global Fund-supported SKPA program managed by the Australian Federation of AIDS Organizations (AFAO). Save the Children Bhutan led the implementation in collaboration with Bhutan's National HIV/Hepatitis & STI Control Program (NACP) and key population-led organizations. The Asia Pacific Coalition on Male Sexual Health (APCOM) also provided regular technical assistance to community-based organizations to operationalize CLM. In late 2021, this coalition started preparing the second phase of the CLM using a draft version of the updated CLM toolkit. A new organization (Chithuen Phendey Association) working for people who use substances has been included in the coalition to increase its reach to networks of key populations. As of March 2022, the coalition was continuing to work closely with the NACP to discuss the second phase. The aim for the second phase is integration of CLM data into the DHIS2 system of Bhutan's Ministry of Health, and the coalition is also planning to collaborate with the Quality Assurance and Standardization Division under the Ministry of Health to explore the opportunity of integrating CLM in the national quality assurance system and to get support for the dissemination and use of the CLM data.

2 Establish or strengthen partnerships with government agencies and other national stakeholders

- As CLM activities focus on health facilities, which are usually managed by government health authorities or operate under regulations defined by the government, it is critical to involve government agencies at the outset and secure their support for CLM.
- CLM should be positioned and presented as an additional and complementarity source of valuable information for government and service providers.
- It is also important to engage other relevant national stakeholders and health authorities at sub-national level, to ensure that CLM findings are accepted and used.

3 Adapt the CLM toolkit, indicators and data collection tools to the country context and train staff who will be responsible for CLM management and implementation

- As this toolkit is generic, it should be reviewed and adapted as needed to the context, including priority needs and available resources. Review and adaptation should be done using a participatory approach that is led by the key population community(ies). After communities have decided what to monitor, involve all relevant government agencies and other national and local stakeholders in agreeing on core indicators and adapting the data collection tools.
- Organize training, in collaboration with community CLM experts, for data collectors and supervisors, data managers and analysts, and other relevant staff.

4 Collect and package data and generate reports

- When data collection tools are ready and staff are trained, data collection can begin. Before you start data collection, consider whether communications activities to raise awareness of CLM among key populations would help to encourage their participation.
- Monitor CLM activities on a regular basis to make sure the system is functioning, especially during the first few weeks.
- Analysis can be reported back to facilities, key population groups, and organizations providing HIV services.
- Once data has been analyzed identify the key messages for HIV services – what are the main findings and what needs to be done to improve services? Consider how best to present the findings and recommendations to different audiences (see figures 5 and 6 for examples).

5 Conduct dialogue about the findings

- CLM is only useful if the findings and recommendations are shared with service providers, including health managers, facility managers and staff, and community organizations. It is also important to share the findings with service users.
- Discussions and meetings with facility managers and staff, and facility users, can be a helpful way to review the findings and agree on what actions will be taken to address concerns raised. It may also be useful to develop a quality improvement or action plan.

6 Engage in advocacy for improvements in HIV services

- Although some gaps can be filled at local or facility level, other issues may need to be addressed at a higher level, for example with the national AIDS program, ministry of health or provincial or regional health authorities.
- Achieving change at this level requires effective, evidence-based advocacy that presents data in a constructive way. Presenting data in a way that is unfairly critical can lead to antagonistic and hostile relationships between key populations and health authorities.
- Ideally community organizations should seek to establish partnerships with institutions and policy makers that can make improvements, and ensure that they understand where the data presented to them comes from, and that it is intended to improve health service delivery.
- In the longer term, to ensure sustainability, advocacy and dialogue with national stakeholders should also explore ways to integrate CLM data into the routine HIV information system.

Collecting, analyzing, packaging, and using data are discussed further below and in Section 4.

Data collection methods

A range of methods can be used to collect data on the client form and the client follow-up form. These include:

Online-survey: Where key populations are comfortable with using technology, filling out an online survey on a mobile phone, tablet or computer is a convenient way to provide feedback on their experience of HIV services. A (usually cloud-based) application is needed to collect the data in a database. Some cloud-based applications have special features for data analysis as well. Most of these applications require a paid subscription and the cost of this should be considered and budgeted for beforehand. Google forms[16] may be a good option, as this application is free and data can be stored in an organization's Google drive if there is enough free space. Another option is SurveyMonkey. Both these applications provide a link to a corresponding questionnaire, which can be easily shared with service users via email, SMS or messaging app or embedded in an existing system such as an online reservation system that is already in place in several Asian cities. Once users access the reservation system and register with the HIV service, the system can automatically send the link to the user's phone so they can complete the CLM form. Alternatively, a direct link to the online survey can be stored in a Quick Response (QR) code that can then be scanned by a health service user, using their smartphone or tablet. The QR code could be included in any print media or social media messages that reach members of key populations.

Suggestion box: For users who do not have access to a mobile phone or who prefer a paper-based form, a suggestion box at health facilities can be used. With this approach, paper forms should be made available at the facility for users to fill out. Signs and instructions should be developed to attract the attention of service users and guide them on how to complete the form and where to leave it. Pens or pencils should be made available as well. The CLM data collection box should be clearly marked and placed in a strategic location on the facility premises that respects the privacy of the user. Additional boxes can also be placed in different locations, such as at a drop-in center or the office of a community-based organization. Boxes must be locked with a key that is kept by the organization in charge of implementing CLM activities.

Face-to-face interview: Sometimes key population service users are unable to read and write or feel uncomfortable filling in a form themselves. For these service users, volunteers or outreach workers could conduct brief interviews. This could be done during routine activities such as outreach in physical and virtual locations, case management, navigation services at facilities, or support groups. Either paper-based or online forms could be used to record the feedback provided. It is particularly important that informed consent and privacy/confidentiality are strictly adhered to in face-to-face interviews (see ethical considerations in section 2).

Phone call or social media interview: If the promotion of CLM is effective and budget sufficient, service users may have the option of contacting CLM staff[17] or volunteers to provide feedback on the services they have used. Contact details such as a telephone number or social media details of hotline services or CLM staff or volunteers, should be included in the promotion of CLM. As with face to face interviews, CLM staff or volunteers can complete the questionnaire on behalf of HIV service users using either paper-based or online forms.

16. Visit this website for further information: https://www.google.com/forms/about/ (accessed on October 7, 2021)
17. CLM cannot be carried out by individuals who are providing services themselves as this poses a conflict of interest

Analysis and presentation of data

Following the AAAQ framework, answers to questions on the CLM client form should be transformed into indicators for availability, accessibility, acceptability and quality of HIV services for key populations. This can be done for all key populations or for specific key populations separately, for each facility or cluster of facilities, or by age group.

For most indicators, the mean score should be calculated. This is the average of all responses for each indicator within a given period of time. Indicator results can be presented in different ways. In figures 4. to 6. below we have included sample data from a fictional health facility, Beach Health Center, to help illustrate how indicators can be calculated and presented.

- **Across all key populations:** so that the overall experience and satisfaction of key populations using HIV services in the area/country can be assessed and tracked over time. To illustrate how to calculate and present data across all key populations, we include a tally sheet of service availability data (indicator A.2.) from quarter 2 (Q2) for the Beach Health Center.

Figure 4. Example of how to calculate service availability from the Beach Health Center

Beach health center service visits during Q2		**A2. Service Availability Tally Sheet**						**All Services Available (Yes/No)**
		HIV confirmatory test (5b.)		Anti-retroviral therapy initiation (5h.)		Anti-retroviral therapy refill (5i)		
Client #	KP Group	Sought?	Received?	Sought?	Received?	Sought?	Received?	
101	MSM	Y	Y					Y
107	FSW	Y	Y	Y	N			N
85	MSM					Y	N	N
143	MSM					Y	Y	Y
156	TGW	Y	Y					Y
162	MSM			Y	Y	Y	Y	Y
84	TGW	Y	N					N
12	FSW	Y	Y					Y
15	MSM					Y	Y	Y
12	FSW			Y	Y			Y
Total Client visits: **10**		Total visits where ALL services were available: **7**						
							Availability score (7/10)	**70%**

In this example, 70% of key population CLM participants received all the HIV services they sought in quarter 2 (Q2) at the Beach Health Center (in this example, services 5b., 5h., and 5i. on the CLM form – HIV confirmatory testing, Anti-retroviral therapy initiation and Anti-retroviral therapy refills). One client (ID #12) sought HIV services twice in the quarter, and both the visits are included in the calculation of this indicator (see section 2., number of service visits vs number of individuals, for more information on this). Another client (#107) sought two services (5b. and 5h.) on the same visit. Because one was available but the other was not available, the overall rating for availability of services was 'no' for this client. According to the definition used here, all services sought need to be available.

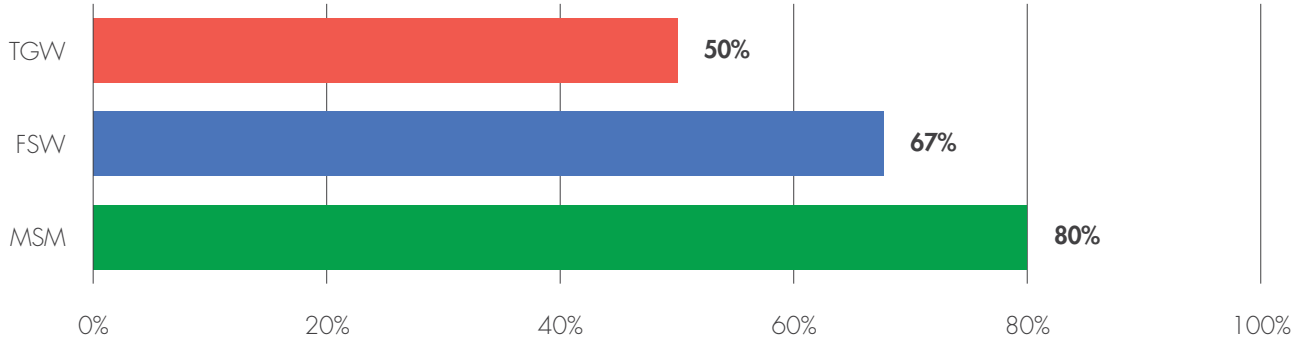
- **By key population:** so that visits to HIV services can be compared for different key populations across facilities. This may highlight differences in service access or satisfaction between key population groups.

Figure 5. below shows the same tally sheet from Beach Health Center in Figure 4., this time with the data disaggregated by key population group, and transformed from a table (top) into a bar chart (bottom). This makes it easier to identify differences in service availability by key population group. In this example, MSM were the most likely to find services available at the Beach Health Center (80%), while TGW were the least likely (50%). Seeing as there were only 2 TGW clients during the quarter, it means only 1 TGW client did not receive all the services they sought, and this number is not sufficient to make any meaningful interpretations (including calculating percentages) of service availability for different key population groups. In cases like this with very low numbers, it may be best to use a longer time period (e.g. combine a whole year's worth of data, like the last four quarters) to make a more meaningful analysis for the Beach Health Center, and/or combine data from several facilities together.

Figure 5. Service availability by key population group from the Beach Health Center

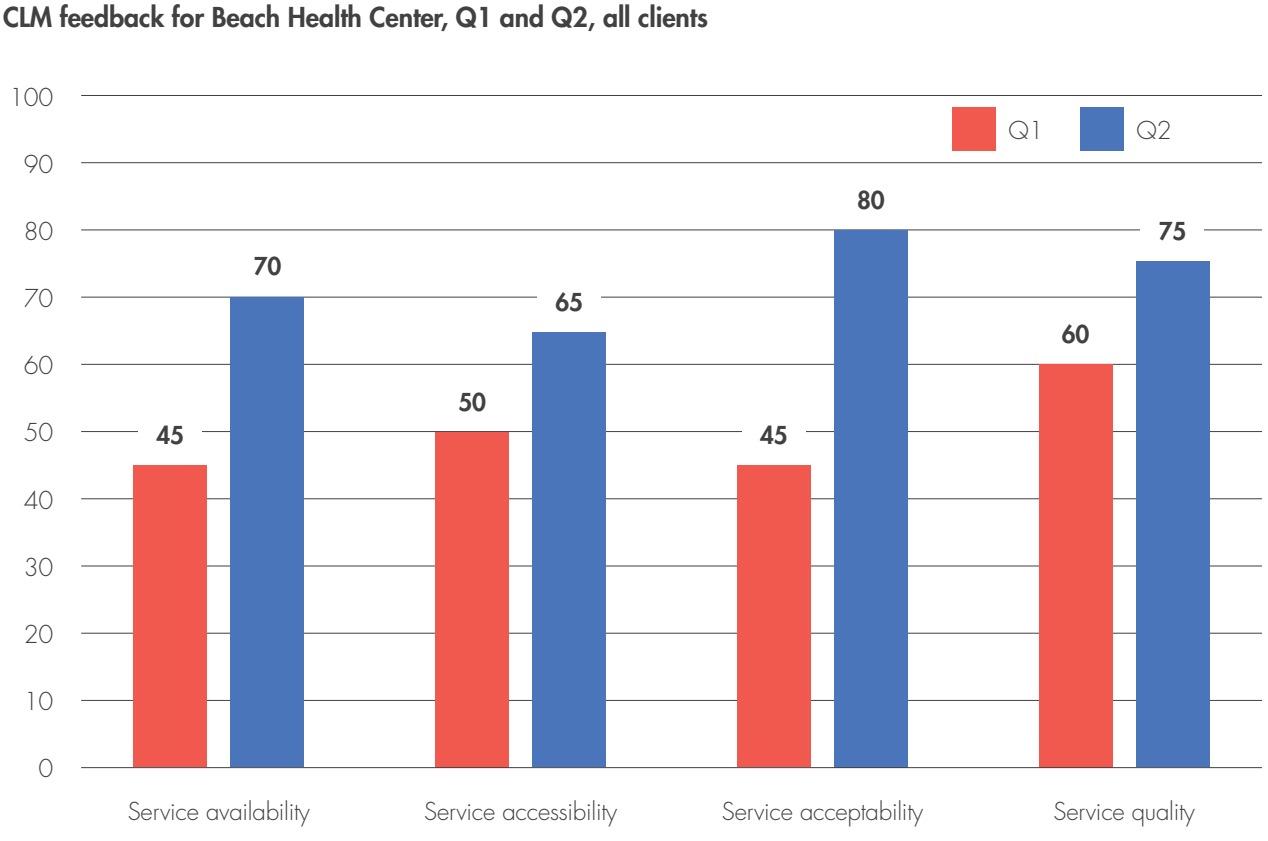
Service availability by KP group	# visits where services were available	# visits during quarter	Service availability score for each group
MSM	4	5	80%
FSW	2	3	67%
TGW	1	2	50%

Service availability by key population group, Beach Health Center, Q2



- **By facility, rural/urban or district/province:** so that service quality at different facilities and other geographical units can be compared. This can be done with individual facilities, but can also be done using a cluster approach, for example, comparing all government facilities with all private/CBO facilities, or comparing facilities in urban areas with facilities in rural areas, or all facilities in one province with those in a different province.
- **By age group:** so the experience of service visits among younger key populations can be compared with those of older key populations. It is important to define age groups for comparison. For example, some guidelines use a cut off of 25 years of age for young key populations, while those aged 25+ are defined as adult key populations.
- **By sex/gender:** so the experience of service visits can be compared between males, females and transgender women and men. Consistently lower scores for one gender at a facility compared to scores from other genders, could indicate a systematic bias, service or training gap that needs to be addressed.
- **By trends over time:** so scores for the same indicator are compared over time to assess whether service ratings are improving, stable or worsening. This can be done at facility level, district level, provincial or state level, or national level. Figure 6 shows the presentation of select CLM indicators at two points in time (quarter 1 (Q1) and quarter 2 (Q2)) for the Beach Health Center. This example shows improving scores for all indicators between Q1 and Q2, which may reflect deliberate efforts to make the service more key-population friendly.

Figure 6. Example of how to present CLM trends from the Beach Health Center



- **By sub-groups of key populations:** if the number of responses is large enough, it may be possible to calculate mean scores for key population sub-groups, such as scores for visits by young female sex workers, compared to older female sex workers or to young transgender women across different states or provinces.

Sharing the findings from CLM data analysis is a critical step to ensure that CLM leads to improvements in the availability, acceptability, accessibility and quality of HIV services. Data can be presented in tables, graphics (e.g. pie charts, bar charts) or infographics, depending on the audience and the message to be communicated. Findings can be shared through reports, presentations, social media platforms and the media. It is important to consider what data is likely to be of interest to a particular audience. For example, CBOs working on transgender health issues or LGBTI rights may be interested in the prevalence of serious incidents experienced by these key populations, while data on AAAQ indicators for all key populations will be of more interest and relevance to HIV service managers.

Analysis of serious incidents, including by category, and of the effectiveness of efforts to resolve these, can also provide useful insights to share with policy makers and service providers. For example, this data can be used to understand what types of incidents are affecting HIV service access or retention, and to what extent these incidents are being effectively addressed. It is important that any identifying information for such cases is removed before data are shared.

4

HOW TO USE CLM FINDINGS TO IMPROVE HIV SERVICES?

Dialogue and Advocacy

In many cases, when areas for improvement are identified through CLM, a constructive meeting or workshop with facility managers and senior staff can lead to immediate changes. In collaboration with key stakeholders at local level, including facility staff, an action plan can be developed for each facility[18] to address areas for improvement, which can then be followed up over time.

Box 2: Making use of CLM data in Timor Leste

In 2019, Estrela+, an independent association of people living with HIV in Timor-Leste, established a response feedback mechanism (RFM) using multiple channels, including suggestion boxes, social media (Facebook and WhatsApp), a hotline, and face-to-face feedback with peers at health facilities, to routinely capture experience from clinic visits. This activity was supported by the Asia Pacific Network of People Living with HIV (APN+) and the Global Fund-supported SKPA program managed by AFAO, with technical support provided by PINOY Plus Association in Philippines.

Estrela+ built a network of partners and stakeholders including the Ministry of Health, referral governmental hospitals in Dili and at municipality level, private clinics, key population-led organizations, and legal and mental health services. The RFM monitors human rights issues, HIV treatment services, factors affecting the accessibility of HIV services and commodities, and demand for HIV-related information. Each report is analyzed and an appropriate response is provided e.g. online or face-to-face counselling, referral to HIV, mental health or legal services, and distribution of ART through community-based differentiated service delivery (DSD) models. During 2019-2021, about 50 people living with HIV who had disengaged from HIV treatment services contacted Estrela+ and were counselled and successfully linked to services, and 15 cases of stigma and discrimination or breach of confidentiality were resolved.

In many countries, Quality Improvement (QI) of HIV services is already an important area of focus for health ministries, and facility-level QI efforts are already underway. Positioning CLM as a tool to strengthen QI can help to secure buy in and support for it. However, collecting, analyzing and sharing data is not always enough to lead to improvements in services. Change may require dialogue and advocacy with decision makers as well as service providers and, more specifically, capacity building may be required to improve the attitudes and skills of health service providers and managers, or to correct misconceptions held by service users.

Advocacy should be done in a constructive and collaborative way, to avoid antagonising government stakeholders and health service managers and providers.

18. See annex 4, template for corrective action plan

If several areas for improvement are discovered as part of the CLM analysis, it is important to prioritize issues that are the most important and easiest to fix, and to identify short-term and longer-term goals. For example, changing opening hours to open on Friday and Saturday evenings may be a relatively easy and quick fix to improve accessibility, if this can be decided at the facility level. Other issues, such as the availability of PEP or PrEP or the lack of access to HIV testing for young key populations may not be so easy to change, as they are related to broader policy decisions. For these issues, it can be helpful to develop clear advocacy goals and an advocacy action plan. Advocacy plans should include working in partnership with other community organizations and networks, and with health facilities, to identify specific service improvements as goals, and develop a plan of action based on the regulatory framework and planning processes overseen by government.[19]

Box 3: Rewarding good quality and success

Whereas advocacy often focuses on weaknesses and gaps that need to be addressed, it is important also to use successes and achievements for advocacy purposes. Praising a particular clinic that has achieved high satisfaction ratings, or has seen an improved rating over time, may be more effective than highlighting the weaknesses of the worst-performing clinic. 'Positive' advocacy could include giving awards to facilities that saw the greatest improvement in satisfaction ratings over the past 12 months, per key population or per age group. The highest scoring facilities could be acknowledged and provided with a medal, certificate or reward of some kind ("Transgender-friendly Facility of the Year", "Sex-worker-supportive Clinic of the Year", "Appreciation Award by Young MSM 2022", etc.). Criteria for such prizes and awards should be determined and discussed in the committee which is overseeing the CLM; the awards could be presented in a special event organized around World AIDS Day or another auspicious occasion.

19. For more on advocacy, see for example (1) *Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS*. International HIV/AIDS Alliance (2013). Accessed at: https://www.iasociety.org/web/webcontent/file/alliance%20-%20advocacy%20in%20action.pdf

Roles and Responsibilities of Community Organizations in Community-led monitoring

Establish or strengthen partnerships with government agencies and other national stakeholders

CLM partnerships include key population networks, non-government organizations and government. It is critical to involve government partners right from the start.

Establish a steering committee or technical working group

A steering committee or technical working group can help gain broad support for CLM – look for an existing steering committee or technical working group for HIV-related monitoring and evaluation/strategic information or human rights and gender, ensuring that key population representatives are also included.

Recruit and train staff to implement CLM

While all key populations can participate in CLM without the need for training, some roles may require training or capacity building such as CLM coordination, data analysis and management, client follow-up, and communication and advocacy.

Collect and package data and generating reports

Translate questions into local languages and validate the translation with service users. Data collected should be analyzed and reported back to the health facilities on a regular basis.

Conduct meetings about the findings with community partners, facility users, facility staff and other stakeholders

During these meetings the findings of the CLM activities can be presented, and actions addressing concerns can be discussed and planned.

Engaging in community advocacy

While many issues can be addressed at local level through dialogue, some issues/concerns need to be solved at higher levels. For these issues advocacy activities can be developed to bring about positive change.

Resources

In addition to the references indicated in the footnotes of this document, we recommend the following CLM-related documents for further reading:

- Advancing Partners & Communities. Community Scorecard Toolkit: Empowering Communities and Healthcare Providers to Partner in Leading Change. Arlington, VA.: Advancing Partners & Communities | 2018 (Accessed on January 11, 2022)
- EpiC Project (FHI 360): Community-led Monitoring Resources | July 2021 (Accessed on January 11, 2022)
- EpiC Project (FHI 360): Community-Led Monitoring Drives Tailored Solutions and Improves Focus on Client-Centered Services: Success Story | August 2021 (Accessed on January 11, 2022)
- Initiative 5% - Expertise France: Collective Learning: Community health observatories | October 2019 (Accessed on January 11, 2022)
- International Treatment Preparedness Coalition (ITPC): How to Implement Community-Led Monitoring: A community Toolkit | 2021 (Accessed on January 11, 2022)
- International Treatment Preparedness Coalition (ITPC): The Community Treatment Observatory (CTO) Model Explained¬–How communities can collect and analyze health data to ensure accountability and drive change | 2019 (Accessed on January 11, 2022) [Summary brief could be also downloaded]
- International HIV/AIDS Alliance. Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS | 2013. (Accessed on March 4, 2022)
- Nimesh Dhungana, LSE, Flora Cornish, LSE, Morten Skovdal,University of Copenhagen, Gitau Mburu, International HIV/AIDS Alliance (report commissioned by the Community, Rights and Gender Department at the Global Fund to Fight AIDS, Tuberculosis and Malaria): Four models of community-based monitoring: a review | 2016 (Accessed on January 11, 2022)
- PEPFAR Solutions Platform: Community-Led Monitoring Tools | March 2020 (Accessed on January 11, 2022)
- RITSHIDZE: Activist Guide - Community-Led Clinic Monitoring in South Africa | 2020 (Accessed on January 11, 2022)
- Stop TB Partnership |UNOPS: Community-based monitoring of the TB response, using the OneImpact digital platform (Investment Package – community, rights and gender) | 2020 (Accessed on January 11, 2022)
- The Global Fund: Resources for Community-Based Monitoring | May 2020 (Accessed on January 11, 2022)
- The Global Fund: Towards a Common Understanding of Community-based Monitoring and Advocacy | February 2020 (Accessed on January 11, 2022)
- U.S. President's Emergency Plan for AIDS Relief (PEPFAR): Fact Sheet on Community-Led Monitoring | 2020 (Accessed on January 11, 2022)
- UNAIDS: Frequently asked Question on Community-led Monitoring | 2021 (Accessed on January 11, 2022)
- UNAIDS: Establishing community-led monitoring of HIV services | 2021 (Accessed on January 11, 2022)
- UNAIDS: Rights-based monitoring and evaluation of national HIV responses | 2019 (Accessed on January 11, 2022)

5

ANNEXES

Annex 1. CLM Client Form

Section 1: HIV/Health Service and Visit Date

CLM form number:			
	Day	Month	Year
1. Today's date			
2. Name of the facility			
	Ward/Village	Town/District	Province/Region
3. Location of the facility			
	Day	Month	Year
4. Date of your visit			

Section 2. Feedback on the service

5. Which service(s) did you seek today?		**Did you receive it?**	
	Service	Yes	No
5a. HIV screening test			
5b. HIV confirmation test			
5c. HIV counseling			
5d. Condom and lubricant supply			
5e. Post-exposure prophylaxis (PEP)			
5f. Pre-exposure prophylaxis (PrEP)			
5g. STI testing/diagnosis and treatment			

	Service	Yes	No
5h. Anti-retroviral therapy (ART) initiation			
5i. Anti-retroviral therapy (ART) refill			
5j. Anti-retroviral therapy counseling			
5k. Viral load testing			
5l. Other HIV case management			
5m. TB services			
5n. Opportunistic infection (OI) management and medicine			
5o. Other (specify)			

6. Was the HIV service location safe and convenient for you?		
7. Are the opening hours suitable for you?		
8. Was the service affordable for you?		
9. Were you treated respectfully by the staff, regardless of your gender, sexual orientation, age or religion?		
10. Did the staff seek your consent for any procedures (examinations, tests etc)?		
11. Did you receive the items (medicine, condoms, information, lubricant etc) you need?		
12. Did you have to wait too long to see the health care provider?		
13. Did you receive all the information you need and were all your questions answered?		
14. Please give a score out of 10 for how satisfied you were with the service (where 1 is for lowest and 10 is for highest satisfaction)	/ 10	

Section 3. Reports of any serious incidents experienced

15. Did you experience any serious incidents at or linked to the service visit?

	Yes	No
15a. Stigma and discrimination		
15b. Violence because you visited the service		
15c. Harrasment (including sexual) from the service staff or other clients		
15d. Breach of privacy or confidentiality		
15e. Refused service because of gender, identity, race, risk behaviour or other		
15f. Pain or distress		
15g. Other		

16. Can you please provide some more details to assist our follow-up?

	Yes	No
17. Do you consent to having a trained staff member or volunteer contact you to help resolve this?		

18. If yes, please provide your preferred mode of contact and details:

First name or nickname	Phone number

Email address	Whatsapp/lime/other social media

Section 4. Client profile

19. When did you last complete this form?

Never	Less than 12 months ago	More than 12 months ago

20. What is your age?

21. What is your gender?
(tick box)

Cisgender male	Cisgender female

Transgender male	Transgender female

Other / do not want to disclose

22. In the past 12 months have you engaged in any of the behaviours listed here?
(tick all that apply)

	Yes	No
22a. Male to male sex		
22b. Female to female sex		
22c. Received money or goods in exchange for sex		
22d. Use of recreational drugs		
22e. Injected recreational drugs		
22f. None of the above		
22g. Do not want to disclose		

23. Do you have a unique identifier code (anonymous client code) that you are willing to share?

Yes, here it is

No or unsure

24. What is your current HIV status?
(tick box)

Negative

Positive

Unsure

Do not want to disclose

Section 5. General Feedback and follow-up

25. What was the best part of your experience at this HIV service?

26. Do you have any advice, recommendations or requests for this HIV service?

Thank you for taking the time to provide feedback on your HIV service experience. Your feedback is important!

Annex 2. CLM Follow-Up Form

Section 1: Follow-up details

1. CLM form number:

2. Name of the facility

3. Location of the facility

Ward/Village	Town/District	Province/Region

4. Date of the CLM report

Day	Month	Year

5. Date of this follow-up

Day	Month	Year

6. Details of individual following up report

Name	Designation (position) e.g. Outreach worker

Organization	Contact details

7. Client age

8. Client gender (tick box)

Cisgender male	Cisgender female	Transgender male	Transgender female	Other / do not want to disclose

9. Client Unique identifier code (if known)

Yes, here it is	No or unsure

10. Client risk behaviours in last 12 months
(tick all that apply)

	Yes	No
10a. Male to male sex	☐	☐
10b. Female to female sex	☐	☐
10c. Received money or goods in exchange for sex	☐	☐
10d. Use of recreational drugs	☐	☐
10e. Injected recreational drugs	☐	☐
10f. None of the above/did not disclose	☐	

	Yes	No
11. Did client consent to having a trained staff member or volunteer contact them for more information on this?	☐	☐

If no, then go to section 6 and enter 'client refuses to continue the case' under final result

If yes, please continue, using the client's preferred mode of contact and details on their CLM form

Section 2. Follow-up attempts

	First	Follow-up
12. Is this the first contact related to this complaint or a follow-up?	☐	☐

13. How are you following up the client?

Phone call/whatsapp/etc	Email	Face-to-face
☐	☐	☐

Other, please specify

☐

14. Did you reach the client?

Attempt 1		Attempt 2		Attempt 3	
Yes ☐	No ☐	Yes ☐	No ☐	Yes ☐	No ☐

If you were not able to reach the client after 3 attempts, skip to section 6 and enter 'could not reach client'

Section 3. Recap of serious incident(s) to be followed up

15. What was the serious incident they reported experiencing at the service?

	Yes	No
15a. Stigma and discrimination		
15b. Violence linked to visiting the service		
15c. Sexual harrasment from the service staff or other clients		
15d. Breach of privacy or confidentiality		
15e. Refused service because of gender, identity, race, risk behaviour or other		
15f. Pain or distress		
15g. Other, explain		

	Yes	No
16. After discussing with the client, was this a serious incident as above?		

Enter any more relevant details here to assist understanding or resolution of the issue

Section 4. Information following successful contact with client

17. Did you refer the client to any of the following services
(tick box)

	Yes	No
17a. HIV or health services	☐	☐
If yes, which health facility?		
17b. Counseling services	☐	☐
17c. Legal services including police	☐	☐
17d. Social welfare services	☐	☐
17e. Other, please specify		

Section 5. Final result from this follow-up attempt

18. Is the case still ongoing or is it now resolved/closed?

	Yes	No
18a. Ongoing	☐	☐

18b. Case resolved or closed because:

Could not reach client ☐ Successful resolution accepted by client ☐ Client refuses to continue the case ☐ Could not successfully resolve the case ☐

Other situation, please specify

19. Please explain in a few words the nature of the follow-up contact and the result

Thank you for taking the time to provide feedback on your HIV service experience. Your feedback is important!

Annex 3. Sample Informed Consent Form

Informed Consent Template for Client Form

Note: this is a template that should be adapted to reflect the local context.

You are invited to provide feedback on the quality of HIV services received during your last visit at one of the health facilities that is part of community-led monitoring efforts. The feedback is being conducted by [*name of your organization*] in collaboration with [*include the name of the agencies collaborating with this project, including ministry of health*]. This feedback should take around 10 minutes to complete.

Your participation is voluntary and you will receive no direct benefits from participating in this survey. However, the findings are intended to help improve the quality of services provided by the health facility. There are no anticipated risks involved in participating in this survey, except for the small risk that you may experience some discomfort or anxiety from recounting and reporting an unpleasant experience.

All your responses are transmitted to [*add where data are sent such as Google survey*] where data are stored and safely encrypted. You do not need to provide any identifying information about yourself; your responses remain anonymous. Only if you identify a serious issue that is in need of follow-up, you will be asked to leave contact details (phone, email, or social media) with us. Only in that case, your responses may no longer be anonymous to us, as a case manager will be asked to contact you directly to learn more about the issue and discuss potential follow-up actions (that may include referrals to additional services). In any case, no names or identifying information would be included in any presentations based on these data, and your responses to this survey remain confidential.

If you have questions or concerns, you can contact our coordinator at this following number [*add full name(s), telephone number and/or social media username*] from [*add operating day/time*]. You may print a copy or take a screenshot of this consent for your records. Please indicate below whether you agree or disagree to participate in this survey:

- You have read and understood the above information
- You are [*add legal age*] years old or older
- You voluntarily agree to participate

☐ Agree ☐ Disagree

Annex 4: Template for CLM action plan

Facility: _____

District/Province: _____

Date: _____

Name and affiliation (organization) of members of the working group developing the CLM action plan:

Name	**Affiliation (organization)**

Issue description (note: one issue/form)

Desired Outcome

Plan

Planned Action(s)	Responsible	Resources needed	Indicator(s)	Date due
1.				
2.				
3.				
4.				
5.				

Annex 5: Code of Conduct for People involved with CLM Activities

I, undersigned, certify that I will comply with the following principles during the preparation and implementation of any of the CLM activities in [*name city, country*]. This code of conduct must be signed by any individual (employee, volunteer or consultant) involved in CLM activities before they commence.

The principles of this code of conduct are:

All individuals, regardless of their age, ethnicity, religion, gender or sexual orientation, involved in CLM activities should be treated with respect and without a discriminatory or judgmental attitude. Individuals involved in CLM activities refers to individuals who are conducting interviews or client follow-up; those interviewed as part of CLM; those contacted by the team but not eligible as per the criteria established; individuals who refuse to participate, or who refuse to answer some of the questions; including healthcare providers and other members of the team.

- Informed consent should be obtained from every participant prior to collecting information from them.
- The only identifier that should collected is a first name or nickname, telephone number, email, or social media username, only if the key population service user wishes to initiate a follow-up contact after reporting a serious issue, and this information is collected only after obtaining consent. No other identifiers such as full name, date of birth, or address will be collected from any participants.
- The confidentiality of all individuals approached or involved in CLM activities must be respected, and efforts should be ensured to keep data in a safe place, including during travel or breaks.
- Data must never be fabricated or altered to replace missing data (i.e., questions not answered by the participant) or to suit a desired outcome.
- No collected or transcribed data (e.g., field notes, transcripts, questionnaires, recorded tape, dataset) should ever be shared with outside persons who are not involved in data collection or analysis, without prior approval of the CLM coordinator.

I have read and understood the above principles and agree to abide by them

Name and Surname: _____

Organization: _____

Position: _____

Date: _____ Place: _____

Signature: _____

[*2 copies: 1 for the staff/volunteer and one kept in the CLM file of the organization*]

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