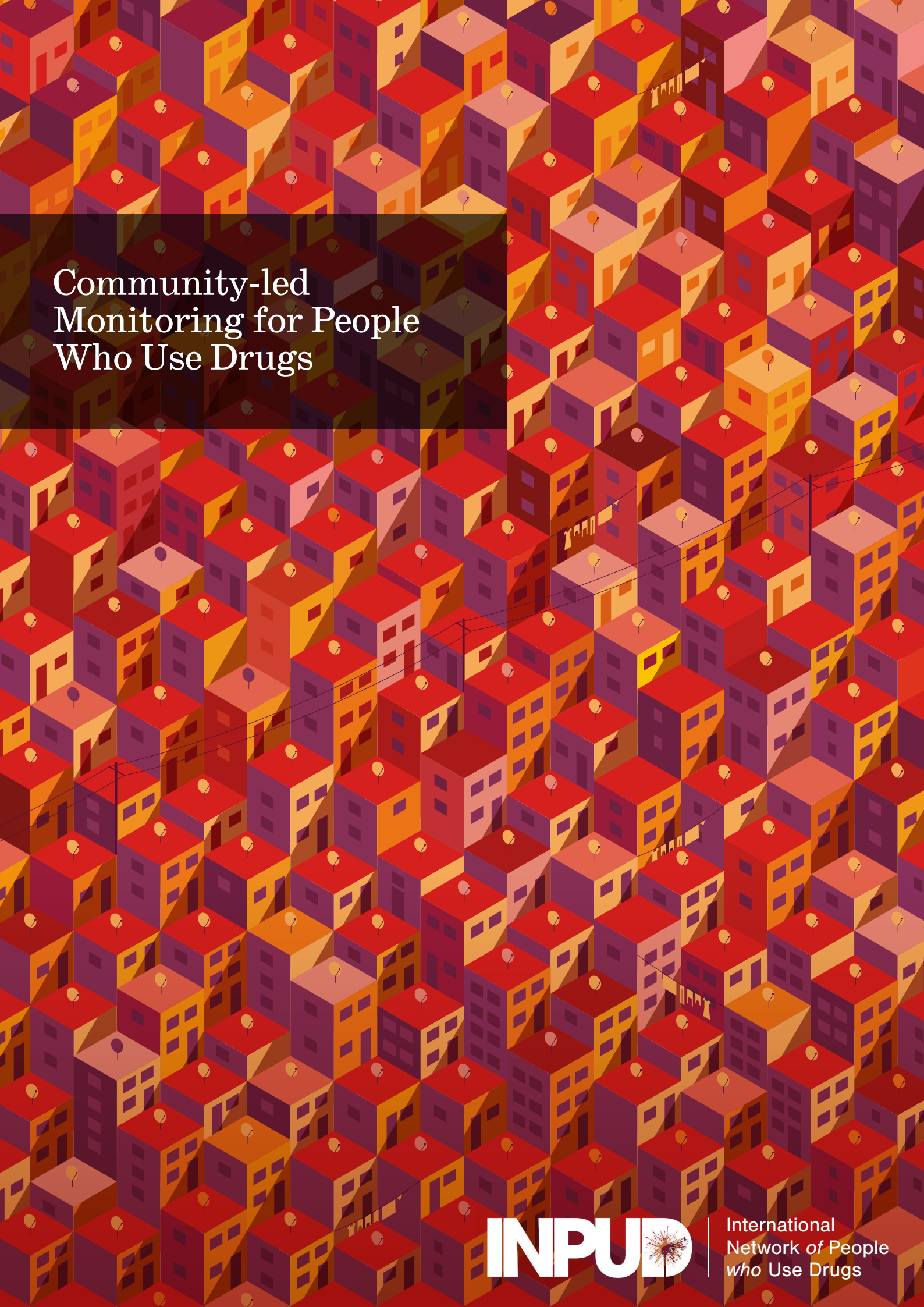

Community-led Monitoring for People Who Use Drugs

INPUD

International Network *of* People *who* Use Drugs

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Glossary of key terms, acronyms and abbreviations

APCASO	Asia Pacific Council of AIDS Service Organisations
ATAC	Alliance Technical Assistance Centre
CLM	Community-led monitoring
CLR	Community-led responses
EANNASO	Eastern Africa National Networks of AIDS and Health Service Organisations
GF	The Global Fund to Fight AIDS, Tuberculosis and Malaria
GHSS	Global Health Sector Strategy
HIV	Human immunodeficiency virus
INPUD	International Network of People Who Use Drugs
ITPC	International Treatment Preparedness Coalition
NSP	Needle and syringe programmes
OAT	Opioid agonist treatment
PEPFAR	The U.S. President's Emergency Plan for AIDS Relief
SANPUD	South African Network of People Who Use Drugs
STI	Sexually transmitted infection
TB	Tuberculosis
TNP+	Thai Network of People Living With HIV/AIDS
UNAIDS	The Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation

Purpose of this guide

This guide was developed to introduce community-led monitoring (CLM) to people who use drugs, to our organisations and networks, and to provide resources to support implementation of and funding for CLM.

CLM is a formal methodology which uses "[...] systematic data collection by communities for evidence-based advocacy to improve accountability, governance, and quality of health services." The core principle of CLM is that it is led and owned by key populations and communities.

There are numerous resources to guide people who use drugs and our communities, organisations, and networks on developing funding requests and implementing CLM including good practices, technical processes, confidentiality, and data safeguarding. They are all included in Annex 1 of this guide. The implementation steps are summarised in the CLM Cycle section. Although most of these resources were not developed specifically for people who use drugs, they can be adapted to fit different contexts.

People who use drugs and our networks and organisations have been at the forefront of human rights advocacy for a long time. CLM however is not intended to replace ongoing advocacy; it offers an additional advocacy avenue to address longstanding inequity, human rights violations, remove policies and laws that feed stigma and discrimination, and address gaps in access to and quality of health and harm reduction services.

1. CD4C, CLAW and EANNASO-ATAC APCASO Consortium (2022). *Community-Led Monitoring. Best practices for strengthening the model* https://oneill.law.georgetown.edu/wp-content/uploads/2022/12/CD4C-CLAW-EANNASO-ATAC-APCASO-Community-led-Monitoring-Best-practices-for-strengthning-the-model.pdf

Background

> *"CLM is taking the evidence and actioning it. If you are collecting data for its own sake, it is wasting time - it will sit in a folder."*
>
> **Angela McBride**, South African Network of People Who Use Drugs (SANPUD)

As a key population, people who use drugs are disproportionately affected by HIV, viral hepatitis, sexually transmitted infections (STI), and tuberculosis (TB). We face social, legal, structural, and other barriers, which increase our vulnerability to these infections. All of these make it difficult for our community to access healthcare and other essential services.

It is essential that people who use drugs are meaningfully involved in the design, implementation, delivery, and oversight of HIV, viral hepatitis, TB, reproductive health, and harm reduction services that aim to reach and engage us, in alignment with the fundamental principle of "nothing about us, without us."

> *"Since 2002, we had been organising and talking to people who use drugs around the country about police enforcement, discrimination, and lack of access to HIV treatment. We brought everyone together to design a strategy, and we formed the Thai Network of People Living With HIV/AIDS (TNP+). Although people who use drugs were at the forefront of the HIV treatment access movement, we were not allowed to get it ourselves."*
>
> **Paisan Suwannawong**, Thai AIDS Treatment Action Group

Initially, harm reduction and healthcare services for people who use drugs could be described as "nothing for us, without us." Based on this principle, people who use drugs have founded local-, regional- and global-level organisations and networks, advocated for laws and policies that uphold our human rights, and delivered effective-peer-led harm reduction services, including underground needle and syringe programmes (NSP). People who use drugs continue to provide responsive, effective services, such as naloxone and drug-checking — often before these interventions are legal and adopted into funded public health initiatives. Before CLM, we were advocating for removal of harmful policies and better access to and quality of harm reduction and health services. We can use CLM as another way to achieve these things.

> *"We wanted people to get the right dose of methadone; they were being tapered without consent, as a punishment for using drugs outside of their methadone programme. After our advocacy, these programmes are more open and accepting - but they are still punitive, and rarely provide takeaways."*
>
> **Paisan Suwannawong**, Thai AIDS Treatment Action Group

CLM is a formal mechanism for something that communities have been doing for decades: sharing information about access to and quality of prevention, testing care, and treatment services for HIV, viral hepatitis, TB, and reproductive health; advocating for their improvement and expansion; and pushing governments to adopt anti-stigma, anti-discrimination, and decriminalisation policies that uphold our dignity and human rights.

CLM arose from the collective recognition that access to, and quality of prevention, testing, care, and treatment services is not always optimal, especially for people from key populations. In its 2022 *Consolidated Guidelines on HIV, Viral Hepatitis and STI Prevention, Diagnosis, Treatment and Care for Key Populations*,[2] the World Health Organization (WHO) notes that, in most countries "[...] inadequate coverage and poor quality of services for key populations continue to undermine responses to HIV, viral hepatitis and STIs."

CLM relies on the leadership and expertise of people who use drugs to increase equity, uphold human rights, and improve accessibility and acceptability of services. Because CLM involves working in partnership with national health authorities and other key stakeholders to find solutions, accountability is built into the model. CLM is not intended to replace advocacy outside of systems. Instead, it provides an additional avenue for within-system advocacy.

CLM has a different purpose from monitoring and evaluation, which provides information for planning, coordination, and implementation of HIV responses, assess their effectiveness, and identifies areas for improvement. In contrast, CLM is intended to:

- empower and upskill communities to routinely collect data;
- identify problems and their solutions; and
- bolster advocacy to improve accountability and service equity, accessibility, quality, and acceptability and uphold human rights.

2. World Health Organisation (2022). *Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations* https://www.who.int/publications/i/item/9789240052390

CLM Core Principles

CLM is all about community leadership and empowerment for people who use drugs. We decide what we want to monitor, and we can use the data we collect to advocate with governments and donors to remove harmful policies and improve healthcare and harm reduction services.

> *"Drug user organisations and networks should be advocacy groups. We deliver services, but this should not close our eyes and our mouths – we have to stand for something. We manage to bring people living with HIV who use drugs to the hospital, where the doctor, the nurses, and everyone else discriminates against them. If we are not there, these people won't get any treatment. If you don't fight for them, there's nobody that is going to fight for them."*
>
> **Loon Gangte**, Delhi Network of Positive People

In August 2022, the Global Fund (GF) held a meeting with 66 CLM implementers and technical assistance providers in Bangkok to develop a global agenda for CLM. The results of the meeting are detailed in a white paper called *Best Practices for Strengthening the Model*,[3] produced by the Community Data for Change Consortium, the Community-Led Accountability Working Group, and Eastern Africa National Networks of AIDS and Health Service Organizations (EANNASO)/ APCASO Asia Pacific AIDS Service Organizations (APCASO)/Alliance Technical Assistance Centre (ATAC). The white paper details eight core principles of CLM, which are "[...] essential requirements for a CLM programme to both achieve impact and avoid common implementation and governance challenges". This definition finds that CLM programmes *must:*

- Be led by directly impacted communities, including people living with HIV, TB, and/or malaria and key populations;
- Maintain local leadership and independence, protecting against programmatic interference from other actors including donors, national government, and other monitoring and evaluation systems;
- Be owned by communities in every stage, including identifying priority issues in the community, defining indicators, establishing preferred channels of communications with partners, and deciding how data are housed and used;
- Include advocacy activities aimed at generating political will and advancing equity, given CLM's fundamental function as a social accountability tool;
- Adhere to ethical data collection, consent, confidentiality, and data security. Data collection must be verifiable, reliable, conducted in a routine/continuous cycle and collected under 'do not harm' principle;

3. CD4C, CLAW and EANNASO-ATAC APCASO Consortium (2022). *Community-Led Monitoring. Best practices for strengthening the model* https://oneill.law.georgetown.edu/wp-content/uploads/2022/12/CD4C-CLAW-EANNASO-ATAC-APCASO-Community-led-Monitoring-Best-practices-for-strengthning-the-model.pdf

- Ensure community monitors are representatives of service users, and that they are trained, supported, and adequately paid for their labour, while maintaining the community independence from the donor; and
- Be coordinated by a central, community-owned structure capable of managing the programmatic, financial, and human resource components of the program.

Definitions of CLM

CLM has become a prioritised funding stream for The Global Fund to Fight AIDS, TB and Malaria (GF), The U.S. President's Emergency Plan for AIDS Relief (PEPFAR), The Joint United Nations Programme on HIV/AIDS (UNAIDS), The Bill and Melinda Gates Foundation, and other donors.

These donors have different definitions of CLM, but it is guided by the same principles: it is community-led and owned, builds power and capacity among communities, and uses data to support advocacy, reinforce accountability, and improve healthcare and policies.

The GF's *Community Systems Strengthening Technical Brief for 2023-2025* describes CLM as " [...] independent accountability mechanisms that are designed, led and implemented by local community organisations working closely with recipients of care and key and vulnerable populations. Through CLM, recipients of care and other local community members use structured data collection and analysis to produce evidence-based recommendations for improved accessibility, acceptability, affordability and quality and impact of health programmes and services.[4]

PEPFAR defines CLM as "[...] a technique initiated and implemented by local community-based organisations and other civil society groups, networks of key populations, people living with HIV, and other affected groups, or other community entities that gather quantitative and qualitative data about HIV services. The CLM focus remains on getting input from recipients of HIV services in a routine and systematic manner that will translate into action and change."[5]

UNAIDS defines CLM as "[...] an accountability mechanism for the improvement of service quality and access. CLM is led and implemented by local community-led organisations of people living with HIV, networks of key populations and other affected groups. In short, CLM is both owned and conducted by the community, and it contributes to the improvement of services that benefit the community.[6]

4. The Global Fund (2022). *Community Systems Strengthening Technical Brief* https://www.theglobalfund.org/media/4790/core_communitysystems_technicalbrief_en.pdf
5. PEPFAR (2022). *Community-led monitoring Factsheet* https://www.state.gov/wp-content/uploads/2020/07/PEPFAR_Community-Led-Monitoring_Fact-Sheet_2020.pdf
6. UNAIDS (2021). *Community-led Monitoring, Frequently Asked Questions* https://www.unaids.org/sites/default/files/media_asset/faq_establishing-community-led-monitoring-hiv-services_en.pdf

CLM Context for People who use Drugs

CLM calls for the leadership of people who use drugs and our organisations and networks, and can strengthen our advocacy efforts.

> *"It is not easy for independent, unregistered, community-led organisations to tell facility providers that their services are horrible."*
>
> **Paisan Suwannawong**, Thai AIDS Treatment Action Group

> *"What are the questions you should be asking? How many times does someone have to say I've been denied a service? CLM is more than a questionnaire – it is tokenism if there isn't an acknowledgement that it has to be inclusive, and context- and community-specific."*
>
> **Angela McBride**, SANPUD

It is important to look at community-specific, local, national, and regional contexts for CLM, as well as the conditions under which people who use drugs will conduct CLM. This is to ensure that they feel — and are — safe and supported. Implementing CLM in hostile environments for people who use drugs is challenging, since many of them are justifiably wary of working in healthcare facilities, due to their own negative experiences and especially compounded by criminalisation, stigma, and discrimination.

Monitoring harm reduction services — NSP, opioid agonist therapy (OAT) programmes, and others — presents challenges for people who use drugs: it may be unrealistic to expect people to monitor the programmes that they themselves rely on due to power imbalances, concerns about reprisal, and lack of access to alternative sites.

A Framework for CLM

People who use drugs have learned about different ways to deliver and improve services from our peers in other countries. This information can direct our advocacy priorities and strategies for CLM.

> *"I don't see anyone who is getting enough syringes in the region [...] I saw this [happen] for the first time, in San Francisco's drug user unions. People come and grab as many needles as they need - that is the real drug user way.*
>
> *NSP should be like what I saw in San Francisco, I've never seen people doing drugs one time a day! Here, people get one syringe a day at best. There are lots of buprenorphine stockouts, but nobody does anything."*
>
> **Loon Gangte**, Delhi Network of Positive People

People who use drugs can use CLM to achieve the change they want to see. CLM may highlight areas for intervention, such as:

- gaps in access to syringes, OAT, and other interventions and services;
- punitive laws, policies, and regulations, human rights violations; and
- prompt advocacy to improve services such as community needs for more and/or different types of syringes, to change policies at OAT facilities, or to recognise the need to sensitise healthcare providers.

It may be helpful to use recommendations from the *IDUIT Brief Guide for People Who Use Drugs*,[7] the World Health Organization (WHO) *Consolidated Guidelines on HIV, Viral Hepatitis and STI Prevention, Diagnosis, Treatment and Care for Key Populations*,[8] targets from the WHO *End TB Strategy*,[9] and the *Global Health Sector Strategy (GHSS) 2022- 2030* targets for eliminating HIV, viral hepatitis, and STI 2022-2030[10] (which was approved at the 75th World Health Assembly,) as well as national guidelines and strategies as frameworks for advocacy. This is to see whether national guidelines are aligned with WHO recommendations, and whether they have been fully implemented, or if the country is meeting targets for NSP and OAT.

7. International Network of People who Use Drugs (2017). *The IDUIT Brief Guide for People who Use Drugs* https://inpud.net/the-iduit-brief-guide-for-people-who-use-drugs/
8. World Health Organisation (2022). *Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations* https://www.who.int/news/item/29-07-2022-who-publishes-new-guidelines-on-hiv--hepatitis-and-sti-for-key-populations
9. World Health Organisation (2015). *The End TB Strategy* https://www.who.int/teams/global-tuberculosis-programme/the-end-tb-strategy
10. World Health Organisation (2022). *Global Health Sector Strategies 2022- 2030 on, respectively, HIV, viral hepatitis and sexually transmitted infections for the period 2022-2030* https://www.who.int/teams/global-hiv-hepatitis-and-stis-programmes/strategies/global-health-sector-strategies

Global Recommendations and Targets

The WHO *Consolidated Guidelines on HIV, Viral Hepatitis and STI Prevention, Diagnosis, Treatment and Care for Key Populations* include these essential health and enabling recommendations:

Essential for Impact: Enabling Interventions

- Removing punitive laws, policies, and practices
- Reducing stigma and discrimination
- Community empowerment
- Addressing violence

Essential for Impact: Health Interventions

- Prevention of HIV, viral hepatitis, and STIs
- Harm reduction, NSP, OAT maintenance therapy, and naloxone for overdose management
- Condoms and lubricant
- Pre-exposure prophylaxis for HIV
- Post-exposure prophylaxis for HIV and STI
- Prevention of vertical transmission of HIV, syphilis, and hepatitis B virus (HBV)
- HBV vaccination
- Addressing chemsex

Diagnosis

- HIV testing services
- Sexually transmitted infection (STI) testing
- HBV and hepatitis C virus (HCV) testing

Treatment

- HIV treatment
- Screening, diagnosis, treatment, and prevention of HIV-associated TB
- STI treatment
- HBV and HCV treatment

Essential for Broader Health: Health Interventions

- Anal health
- Conception and pregnancy care
- Contraception
- Gender-affirming care

- Mental health
- Prevention, assessment, and treatment of cervical cancer
- Safe abortion
- Screening and treatment for hazardous and harmful alcohol and substance use
- TB screening and prevention

GHHS Targets include:

- The number of needles/syringes distributed per person who injects drugs per year should be 200 by 2025, and 300 by 2030 (as part of a comprehensive harm reduction program).
- The percentage of countries which have punitive laws and policies should be less than 10 percent by 2025 and onward.
- Reducing the number of new HCV infections among people who inject drugs to 3 per 100 people by 2025, and to 2 per 100 people by 2030.

The End TB Strategy 2030 Targets

- Reducing TB incidence by 80%
- Reducing TB deaths by 90%
- Eliminating catastrophic costs for TB-affected households

CLM and Human Rights

Gathering CLM data on the impact of restrictive, stigmatising, and punitive laws, as well as policies and regulations that exacerbate barriers faced by people who use drugs can strengthen advocacy to eliminate such measures. It is essential to assess human rights violations, discrimination, and the impact of deeply rooted stigma among service providers, which may result in intentionally prolonged waiting times at healthcare facilities, withholding care and treatment, or sharing personal information with law enforcement and other authorities. Your CLM may include questions that assess stigma and discrimination, such as:

- Have you experienced discrimination based on your drug use during the past 12 months?
- Has medical care been withheld because of drug use and/or HIV status during the past 12 months?
- Has your confidentiality been violated at a healthcare facility?
- Have you been made to feel unwelcome at any programme or service because of drug use?

For more information, see The *Fight for Accountability: Opportunities to Engage in Human Rights Advocacy for INPUD* report.

REAct — A Tool for Monitoring Human Rights

Frontline AIDS created REAct (Rights- Evidence-Action), a GF-supported, community-led monitoring tool to measure human rights violations, stigma, and discrimination among people who are members of key populations.[11] Although REAct was developed to focus on HIV, it can be adapted and used by people who use drugs to monitor human rights and harm reduction services, to provide your community with the necessary data to advocate for changes, and to inform quality of programmes and policies at national, regional, and global levels. REAct can be used to:

- Help identify and document emergency responses and support;
- Ensure that services are confidential;
- Facilitate support and follow-up;
- Provide evidence to improve access to HIV and other services; and
- Improve understanding and realization of human rights.

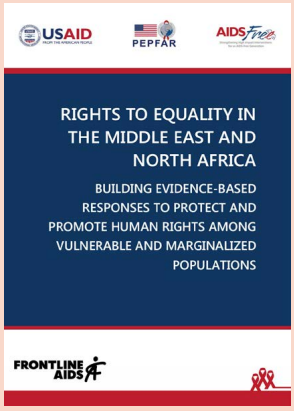
REAct describes the type of incidents (denial of health, legal, and other services, such as protection by police and violence – including sexual assault and physical harm); identifies perpetrators (government official, local authority, law enforcement, prison staff, healthcare staff etc.), and provides categorisation for the types of human rights violations (such as criminalisation

11. Frontline AIDS (2019). *REAct User Guide* https://frontlineaids.org/wp-content/uploads/2021/09/REAct-Guide_FINAL_updatedSep2021.pdf

and enactment of punitive laws that target people who use drugs, stigma and discrimination in workplace and at healthcare facilities gender inequality, and others).

REAct in the Middle East and North Africa[12]

As a part of the Rights to Equality project launched in 2019,



with the support of USAID, civil society partners in Lebanon and Tunisia have documented 240 human rights cases using REAct tool. The Tunisian Association for the Fight Against HIV/STDs used REAct to collect and respond to a total of 82 human rights cases, while the Tunisian Associations for Justice and Equality) dealt with 104 human rights cases.

The key issues that emerged in Tunisia were homelessness among the LGBTI community, and the need for housing assistance for migrants from sub-Saharan Africa and Tunisian people living with HIV.

For more information, including how to implement REAct, see the guide.

12. Frontline AIDS (2018). Strengthening High Impact Interventions for an AIDS-free Generation (AIDSFree) Project https://publications.jsi.com/JSIInternet/Inc/Common/_download_pub.cfm?id=24003&lid=3

The CLM Cycle

CLM is a framework for communities that can empower them to identify advocacy priorities, document gaps in access to and quality of services and the impact of harmful laws, policies, and regulations, and to use this information to identify solutions, advocate for improvements, and work with duty-bearers to implement these changes.

> *"Saying that there aren't enough needles doesn't fix why there is a cap on the amount of needles. People who use drugs still face discrimination from law enforcement and medical service providers. Although this has already been noted, and there has already been advocacy, CLM adds evidence to advocacy for getting government support for evidence-based interventions for people who use drugs."*
>
> **Angela Mc Bride**, SANPUD

The foundation of CLM rests with communities, organisations, and networks of people who use drugs. We select advocacy priorities, we choose the programmes and/or policies we want to monitor, the information we need to gather to assess programmes and/or policies, and we develop and implement advocacy and follow-up strategies to improve access to, and quality and impact of harm reduction and health services.

CLM FOR PEOPLE WHO USE DRUGS

Examples of ongoing CLM initiatives for people who use drugs include Pereboi in Kazakhstan, which has a website where people report human rights violations, discrimination, and shortages of HIV, hepatitis C, and OAT commodities (https://pereboi.kz). At the same time, Hope and Trust organisation in Ukraine runs an OAT hotline, which provides information on harm reduction, drug treatment, and HIV and TB services to community members, and helps them overcome challenges in accessing health services.

The CLM cycle can be divided into stages. These stages are the pre-data collection, data collection and analysis, developing solutions and advocacy, monitoring and follow-up. The steps and processes involved with each stage are described below. Additional information is included in Annex 1.

Pre-data Collection – Building a Foundation for CLM

The first step is selecting a community-based organisation to lead CLM implementation and programme management. The lead organisation must not have a conflict of interest, such as being the service provider that will be monitored. This is to ensure that your CLM is fully independent. The lead organisation will need to write and manage grants and programmes, and may need to build its capacity to do so.

Practical tip: to get started, it's important to ensure that your community is aware of your interest in CLM, and plan to implement CLM as a way to inform collective advocacy. Convene discussions with community members to define the need for CLM, identify their key issues — such as access to and quality of services and human rights — and select a lead organisation.

The lead organisation will:

- Solicit funding for CLM (such as from the Global Fund and PEPFAR, who have prioritised funding streams for CLM; see Annex 1 for more information).
- Oversee development of a workplan and budget for CLM.
- Convene community meetings to explain the concept and steps of CLM and finalise it. During this stage, work to reach consensus between stakeholders on the concept and structure of your CLM, and how it will be implemented. This means being clear about:
  - The objective of your CLM - what will be monitored and assessed (provision and quality of harm reduction services, access barriers to treatment schemes, stigma and discrimination, human rights violations, etc.)
  - How you will ensure that data is confidential, and privacy is safeguarded (see *Informed Consent, Data Security and Confidentiality* for more information).
  - Whether you require ethical approval, and who it will be from, when and how you will obtain it.
- Introduce government representatives, donors, and/or other duty-bearers to CLM, establish a framework for collaboration, and develop a plan to incorporate CLM into decision and policy making. Establish formal collaborations with networks and other groups.
- Provide trainings: capacity-building for CLM includes work planning, performing monitoring and evaluation (M&E), data collection, storage, analysis and use, financial management, and governance to ensure that your community has sufficient knowledge about approaches to, and tools for monitoring.

Practical tip: You can reach out to the Global Fund, PEPFAR, International Treatment Preparedness Coalition (ITPC), and other organisations to search for funding support and opportunities to apply for technical assistance on CLM (also see Resources section of this Guide).

- Convene community meetings and focus groups to share information on global and national guidelines, goals and targets, and work collaboratively to identify the advocacy priorities for guiding your CLM.

Practical tip: Identify skilled facilitators who are knowledgeable about CLM and community needs. Use a few key questions that may help you plan your CLM, such as:

- What are the primary objectives for your CLM, i.e., which barriers do we want to monitor and why?
- Which interventions/services will we focus on?
- Will our CLM monitor issues in a single area, or be related to one disease, or will it adopt an integrated approach?

- Consult with other key populations to ensure that your CLM will not duplicate their ongoing work, and for alignment on common issues.
- Your CLM can include monitoring policies, practices, and attitudes that keep people who use drugs from accessing services.
- When you decide on the focus of your CLM, work closely with community members to develop a basic set of questions, such as about access to and quality of NSP, OAT, and other programmes for people who use drugs in your country or region. (See Tables 1 and 2 for sample questions).

Table 1. CLM Sample Questions

• Are you satisfied with the quality of commodities (such as needles and syringes, condoms, lubricants, masks, hand sanitiser) that you have received in the past six months?
• How safe did you feel during your last visit to the program/facility (unsafe/fairly safe/ safe/very safe)?
• How would you rate the courtesy and helpfulness of the drop in/treatment centre staff, on a scale of 1 (poor) to 5 (excellent)?
• How useful was the information you received during your last visit (not useful/fairly useful/useful/very useful)?

South Africa's Ritshidze project — which was developed by people living with HIV, activists, and their networks and organisations — monitors and improves HIV and TB clinic services. The project developed a specific survey for people who use drugs, which it uses to monitor discrimination towards, and accessibility of specific services for people who use drugs. The complete survey is available here.

Table 2. Monitoring Areas and Potential CLM Survey Questions (Adapted from: Ritshidze Activist guide: Community-Led Clinic Monitoring in South Africa – The Ritshidze project, 2020)

Access to Medicines and Shortages/ Stockouts	• Are you aware of any stockouts or shortages of medicines and other medical supplies in the centres/clinics you attend? • Do you know if clients leave the clinic without getting the medicines they needed? • If there was a shortage, were people given alternative medicines or short-term supplies?
Facility hours and waiting times	• How long do you wait at the clinic? • Are the queues for the clinic long? • Is it safe to wait outside the clinic gates before the clinic opens? • What time does the clinic usually stop seeing clients? • Do you think this facility is open long enough to meet client needs?
Access to healthcare services	Have you, or anyone you know, faced the following challenge to accessing healthcare: • Been refused access to services for not having an identity document? • Been denied access to services for being unable to pay for them? • Been refused services because of drug use? • Been refused services because of being part of the LGBTQIA+ community?
Stigma and discrimination	• In the last year, has this facility refused to provide services to you because you are a person who uses drugs? • Are the staff at this facility friendly and professional towards people who use drugs? • On a scale of 1 to 5, how comfortable do you feel using this facility? • Do you think that this facility respects people's confidentiality and privacy?

- Develop indicators, both quantitative and qualitative — which measure what is happening in a certain situation — based on your questions. Quantitative indicators describe amounts, such as the number of needles/syringes that people were able to access at the NSP. Qualitative indicators describe an experience, such as how someone was treated at a healthcare facility.

Practical tip: One of the strengths of CLM is the opportunity to include qualitative data, which provides a fuller picture of access to, and quality of services, and this strengthens your advocacy. This information can help you learn more about people's perspectives, such as about how long they have to wait for services, their safety and confidentiality at the facility, staff attitudes, medicine stockouts and/or shortages.

Table 3. Sample of CLM Indicators for NSP (Adapted from: Monitoring Quality and Coverage of Harm Reduction Services for People Who Use Drugs: A Consensus Study)[13]

Quantitative	Qualitative
Number or percent of programme beneficiaries who were given the requested amount of needles/syringes	On a scale of 1 (poor) to 5 (excellent), how would you rate the quality of services you received?
Number or percent of programme beneficiaries offered the type of needles/ syringes they wanted	What could improve the quality of NSP service?
Number or percent of programme beneficiaries offered	On a scale of 1 (poor) to 5 (excellent), how would you rate your access to NSP services?
Number or percent of programme beneficiaries offered take-away naloxone	How could NSP access improve?
Number or percent of programme beneficiaries offered information on safer injection	What makes you feel safe/unsafe while accessing NSP services?
Number or percent of programme beneficiaries offered other information or services (specify- such as referrals, counselling, and testing for HIV, hepatitis C, TB, etc.)	What would make you feel safer while accessing NSP services?
Number or percent of programme beneficiaries who were offered the opportunity to provide their feedback on the services they received	Did you feel you were treated respectfully by the staff?

- Develop data collection software, tools, policies, and trainings.
- Hire and train your data collectors. Capacity-building for data collectors should provide an understanding of human rights, as well as training to develop and use different data-gathering tools, and skills to interview and facilitate focus groups.

13. Wiessing, L., Ferri, M., Běláčková, V. et al. (2017). Monitoring quality and coverage of harm reduction services for people who use drugs: a consensus study. Harm Reduction Journal 14 (1). https://doi.org/10.1186/s12954-017-0141-6

Practical tip: Identify, recruit, and train people who will be collecting data from your community who have access to, and an understanding of the services you will be monitoring.

To learn more about CLM-focused trainings, have a look at the opportunities offered by the Global Fund Community Rights and Gender Strategic Initiative[14] and its regional platforms, and from UNAIDS, PEPFAR, ITPC and others (see Resources).

Data Collection and Analysis

After your community has decided on its advocacy priorities, and developed a set of questions and indicators for your CLM, the next steps are choosing the sites and scope of CLM (such as local, national, or regional), and deciding which tools you will use for collecting your data.

DATA COLLECTION TOOLS

There are many ways to collect data for CLM, such as through focus groups, surveys, and interviews. For example, individual testimonies can assess the quality of healthcare and other services, and a personal story can raise the voices of community members who are struggling to access health services in a way that regular monitoring cannot.

Data can be collected by different methods (focus groups, surveys, interviews) and in different settings (clinics, harm reduction programs, community centres, etc.).

Focus group discussions can provide meaningful insights about people's beliefs, perceptions, attitudes, experiences and reactions that other data collection tools are not able to capture. For example, a network of community-led organisations working on economic and social justice can collaboratively monitor economic, cultural, and social rights using door-to-door paper surveys, Right to Information requests, SMS, text messaging and other web-based methods, as well as photos and videos and participatory methods (such as personal stories and diaries), and by mapping problems, power, and communities.[15]

Data Security, Confidentiality, and Privacy

Data security, privacy, and confidentiality are essential to people who are members of key populations, including people who use drugs, because being identified as member of a key population community can lead to discrimination, stigma, and legal repercussions.

The key principle of CLM data collection is anonymity. To ensure this, you can use *unique identifier codes (UIC).* Nonbiometric UICs can be a set of codes, or a physical card with a UIC that stores encrypted data. Biometric UICs are commonly generated from fingerprint or facial recognition

14. The Global Fund (2020). Community, Rights and Gender Strategic Initiative Update https://www.theglobalfund.org/media/9948/crg_2020-06-strategicinitiative_update_en.pdf
15. ESCR-Net Monitoring Working Group (2017). Communities Telling Their Own Stories: Our Experience with Community-Led Monitoring https://constitutionsmatter.org/media/communities_telling_their_own_stories_our_experiences_with_community-.pdf

patterns. INPUD, alongside with UNAIDS and other bilateral partners, has been advocating strongly against use of biometrics, because of risks related to stigma and punitive legal frameworks, especially for groups that have been criminalised.[16]

Switching from using someone's personal information to a UIC ensures the anonymity of their information and can improve linkages to treatment services, facilitate management of medicine stockouts, and minimise loss to follow-up.

Data protection procedures must be established and followed strictly by everyone involved in all stages of CLM — from setting it up, to collecting and analysing data, and for focus group and interview participants, and any other people who provide information for your CLM. This is to improve the processes of providing and taking of information. It should be clear to everyone implementing and participating in CLM at each step how data are being processed, what hazards exist that might potentially compromise CLM data security, and what is being done to mitigate them. As such, develop and implement standard procedures for safeguarding, storing, and/or discarding data after it has been entered into the database across all methods of data collection.

Informed Consent

All CLM participants must provide informed consent before they provide any information. Part of the consent process is verbally explaining the process, including that they have the right to withdraw their consent at any point.

DEVELOPING SOLUTIONS AND ADVOCACY

CLM provides the community with a mechanism to build advocacy and justify the need for programmatic and policy shifts in the area you are assessing. Once the CLM is completed, its results should be disseminated among the key partners and organisations involved in the programme implementation, such as: GF principal and/or sub-recipients, Ministry of Health, bilateral partners, etc. Once your CLM has revealed human rights violations and/or gaps in access to, or quality of services, the next step is using your data for advocacy in many ways. This may include to uphold accountability for services, programmes, laws, regulations, and policies through campaigns, public speaking, meetings, reports and engaging with the media to increase the visibility of your advocacy.

16. Kavanagh et al. (2019). Biometrics and public health surveillance in criminalized and key populations: policy, ethics, and human rights considerations. *Lancet HIV 2018*. https://pubmed.ncbi.nlm.nih.gov/30305236/

Figure 1. The CLM Advocacy Cycle

Convene meetings between the lead organisation, community-led organisations and networks and other stakeholders to share data and identify areas which require improvement.

- Disseminate the results from your CLM among your key partners, networks, and organisations involved with its implementation, such as: GF principal and/or sub-recipients, Ministry of Health, bilateral partners, etc. Use the data you have collected to develop an actionable advocacy plan for changing programs, services, regulations, laws, and policies.
- Develop data-led, actionable solutions to improve service access and quality and/or for removal of policies that have a negative impact on human rights, and craft advocacy messages and strategies.

- Disseminate advocacy messages and bring them to the attention of decision-makers through participation in policy and decision-making forums, meetings, and through community networks and the media.

CLM and IDUIT in Moldova[17]

In 2020, Puls Communitar, a network in Moldova, implemented CLM to assess the basic package of harm reduction services for people who inject drugs, based on recommendations from the IDUIT guide. The key outcomes of this CLM were:

- The national guidelines had been recommending providing fewer needles (240 per person, per year) than what WHO had been recommending (300 per person, per year).
- Access to NSP is hindered by repressive drug policies, police violence, and prosecution.

Puls Communitar used their CLM data to develop a number of advocacy steps, such as: 1) forming a coalition to develop an action plan, and identify relevant allies and opponents; 2) developing a concrete proposal for reviewing the data and discussing it with other key populations; 3) identifying an opportunity for revising the national standards and guidelines in accordance with IDUIT.

In addition, communities have used CLM to:

- Advocate successfully for the removal of user fees for HIV services in Cameroon;[18]
- Advocate successfully for Sierra Leone's National AIDS Control Program to add a new indicator on HIV treatment failure;[19] and
- Inform and launch reports covering monitoring and suggestions for improvement of key population-friendly and specific services at healthcare facilities in South Africa.[20]

MONITORING AND FOLLOW-UP

Your CLM should continue its monitoring after it has collected its data and conducted advocacy. This is to ensure that duty-bearers are implementing promised changes in services, laws, policies, and regulations, and to assess the impact of your advocacy. In addition, follow-up by sharing information with your community (about the data your CLM has collected, how it has used this data for advocacy, and the outcomes of its advocacy), and discuss emergent advocacy areas so that your CLM can be responsive to evolving community priorities.

17. Eurasian Harm Reduction Association (2021). *Report on community-led monitoring of national standards of NSP services for people who use drugs in the Republic of Moldova* https://harmreductioneurasia.org/wp-content/uploads/2021/10/catalog_.pdf
18. CLM- RéCAP+ (2022). Community-Led Monitoring on the Elimination of User Fees on HIV Services in Cameroon https://clm.recap.cm/assets/img/dashboard/dashboard-janvier.pdf.
19. Baptiste S. (2022). Community data matters: A look into community-led monitoring. 24th International AIDS Conference, Montreal, Session PR09.
20. Ritshidze 2022). Community-Led Monitoring Programme in South Africa Kwazulu Natal ¬State of Health Report https://ritshidze.org.za/wp-content/uploads/2022/11/Ritshidze-State-of-Health-KwaZulu-Natal-2022.pdf

Conclusion

CLM has become a prioritised funding stream for donors, providing organisations and networks of people who use drugs with an additional opportunity to remove punitive laws, regulations, and policies, and improve health and harm reduction services for their communities.

Communities are often the first to detect disruptions or problems in accessing healthcare and other necessary services. For the community of people who use drugs, CLM can help build their capacity to collect data, analyse it, and advocate for improvements in harm reduction and other services they use on daily basis. In return, they can use this for advocacy with decision-makers and duty-bearers to ensure their needs are met, and to remove harmful policies, laws, and regulations.

Annex 1 Resources

Annex 1 includes information on funding sources for CLM, how to establish CLM, and on the technical aspects of CLM, such as software for data collection, data security, and data analysis, and how to develop indicators.

Funding for CLM

The GF *2023–2028 Global Strategy*[21] recognises CLM as "[...] a critical source of country-level data for decision-making. The Strategy leverages CLM and advocacy to "[...] inform the design and evaluation of programs [...] and enhance understanding of how services are performing for communities," noting that "[...] particular emphasis will be given to supporting key and vulnerable populations to identify and monitor local barriers and advocate for improved quality, accessibility and affordability of services, including the results and impact of human rights and gender-related programming."

The GF's updated guidance for designing and submitting responses is available at Design and Submit Funding Requests available here.

PEPFAR requires all programmes to develop, and support and fund a CLM platform in close collaboration with independent civil society organisations and host country governments. PEPFAR's Five Year Strategy which, includes the role of CLM, is available here; also see: *Excerpt from PEPFAR COP 20 Guidance: Section 3.3.1.2 Community-led Monitoring for Patient Experience* (pgs. 95-99) from the Office of the United States Global AIDS Coordinator and Health Diplomacy.

21 The Global Fund (2022). The Global Fund Strategy 2023-2028. https://www.theglobalfund.org/media/11612/strategy_globalfund2023-2028_narrative_en

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The International Network of People who Use Drugs (INPUD) is a global peer-based organisation that seeks to promote the health and defend the rights of people who use drugs.

INPUD will expose and challenge stigma, discrimination, and the criminalisation of people who use drugs and its impact on the drug-using community's health and rights. INPUD will achieve this through processes of empowerment and advocacy at the international level, while supporting empowerment and advocacy at community, national, and regional levels.

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