COMMUNITY-LED MONITORING OF HIV AND HARM REDUCTION SERVICES FOR PEOPLE WHO USE DRUGS

Guide for CLM Implementers

2023

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ATAC	Alliance Technical Assistance Centre
ATS	Amphetamine Type Stimulants
C19RM	The Global Fund's COVID-19 Response Mechanism
CBO	Community-based organisation
CCM	Country Coordination Mechanism
CLM	Community-Led Monitoring
CLO	Community-led organisation
CSO(NGO)	Civil society organization or non-governmental organisation is any non-profit, voluntary citizens' group which is organized on a local, national or international level.
EDM	Electronic Dance Music
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HTS	HIV Testing Services
IBBS	Integrated Bio-Behavioural Surveillance
IEC	Information, Education and Communication
ITPC	International Treatment Preparedness Coalition
KP	Key Populations
LGBTIQ+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer/Questioning, Asexual and other sexually or gender diverse people or people with nonheteronormative / nonbinary sexual and/or gender identities
MSM	Men who have sex with men
NGO	Non-Governmental Organisation
NSP	Needle and Syringe Programs
OAT	Opioid Agonist Treatment
OCF	Optimized Case Finding
OST	Opioid Substitution Therapy
PAS	Psychoactive Substances
PEP	Post Exposure Prophylaxis
PEPFAR	The United States President's Emergency Plan for AIDS Relief
PLHIV	People Living with HIV
PrEP	Pre-Exposure Prophylaxis
PMTCT	Prevention of Mother-To-Child Transmission of HIV
PWID	People Who Inject Drugs
PWUD	People who Use Drugs
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
SUD	Substance Use Disorder
SW	Sex Worker
TB	Tuberculosis
UIC	Unique Identification Code
WHO	World Health Organisation

Purpose of the guide

The **purpose** of this guide is to **assist** representatives of CSOs, CBOs, community-led organisations (CLOs), activist groups, and other relevant stakeholders worldwide who intend to engage in or are already implementing **community-led monitoring** services within disease elimination programs. It **offers** an overview of issues related to HIV **prevention** and harm reduction as important aspects of HIV response and thus – a crucial focus for CLM initiatives.

This resource is also valuable for TA providers, governmental institutions, donors, and technical agencies supporting CLM, helping them understand the processes involved and plan their programs accordingly.

The guide is not exhaustive but serves as a starting point, divided into sections that cover aspects such as – what harm reduction programmes exists, what should be monitored, how it can be monitored and how the collected data can be used afterwards to inform and advocate for change.

Target audience / who should use this guide

This guide is designed for representatives of key and other affected populations in different corners of the world that are planning to or are less experienced but have an intention to engage in community led monitoring of HIV prevention / harm reduction services.

How to use this guide

This document is intended as a reference guide. The reader can select one chapter of interest or use it holistically to gain an overall picture of planning for and carrying out CLM of harm reduction services.

1. Introduction

This guide was developed by the **Alliance Technical Assistance Centre (ATAC)** with support from the **Global Fund** under the **Community-led Monitoring** investment of the **Global Fund's COVID-19 Response Mechanism (C19RM)**.

Most of the available resources related to community-led monitoring (CLM) focus on **treatment** of HIV infection, while **prevention**, a crucial part of the epidemic response, has not received sufficient attention. This guide is designed to support communities most affected by HIV in the monitoring of HIV and harm reduction interventions targeting people who use psychoactive substances (PAS).

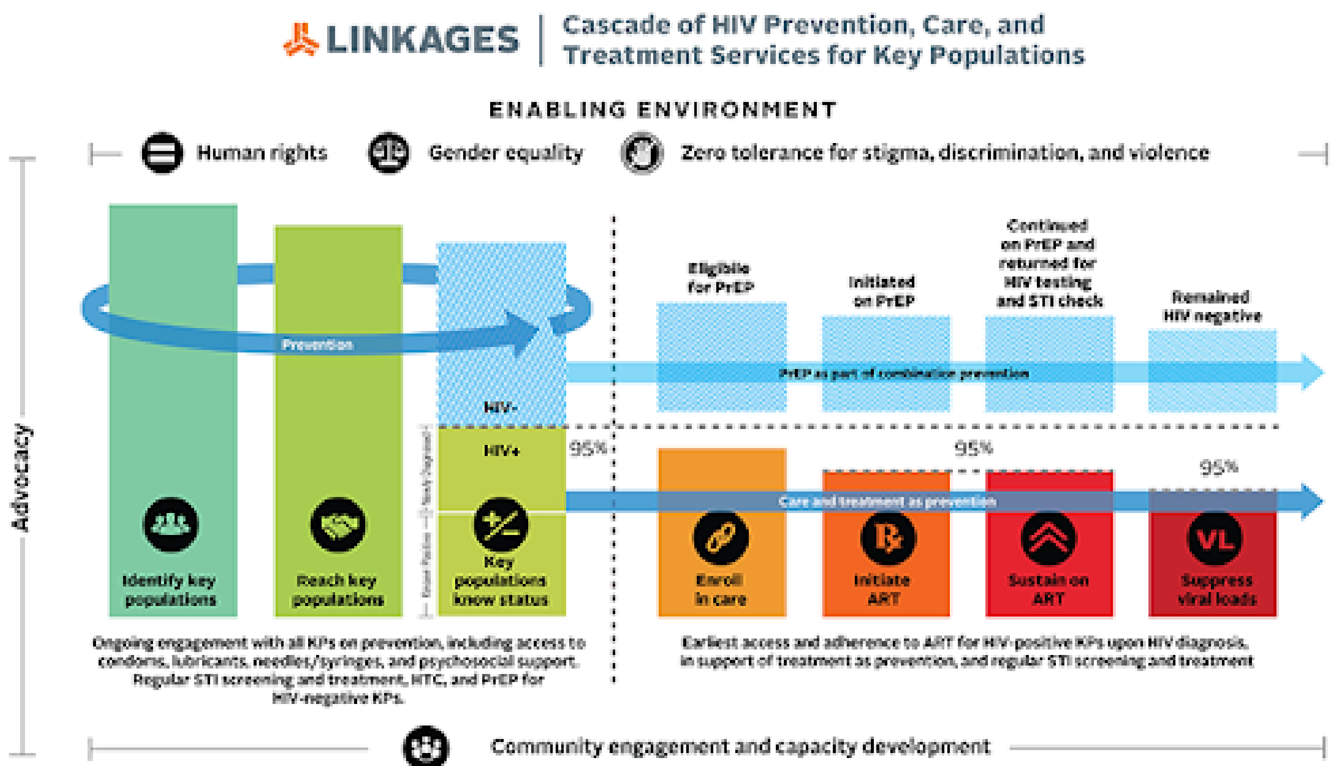
The guide includes key principles, explanations, tools and practical examples of specific issues that may require community monitoring to ensure relevance, effectiveness and inclusivity of HIV and harm reduction services offered to people who use drugs.

The core of HIV related work among people who use drugs (PWUD) is based on harm reduction concepts and interventions. Harm reduction and HIV services are two overlapping areas of work that borrow many of the key elements from each other. On one hand, harm reduction is broader than HIV interventions as the spectrum of harms associated with PAS use, apart from HIV infection, includes a variety of other physical and mental health challenges, sexual and reproductive health, violence, stigma, discrimination and other social problems. Effective HIV prevention, treatment and care in the community of PWUD may not be sufficiently successful if these other challenges facing PWUD communities are not adequately addressed. On the other hand, HIV-related work includes a number of elements that may not usually be identified as harm reduction, such as prevention of sexual transmission of HIV. However, in order to appeal to the clients, harm reduction programmes do need to address sexual and reproductive health and various other needs of PWUD community, including the essential humanitarian needs in times of crisis.

In addition to this, communities defined based on high-risk behaviours often overlap, and addressing the needs of various segments of the community of PWUD requires considering and addressing aspects of HIV prevention and care related to key populations other than PWUD, including sex workers (SW), LGBTIQ+ or people in prisons and other closed settings. Crucial to both HIV prevention and harm reduction is the understanding that abstinence (from sex or drug use) should not be required as a precondition for support.

HIV prevention is an essential part of the HIV response. Without effective prevention, the population of people living with HIV continues to grow, leading to suffering, increasing deaths, overstretching the health system and spending on treatment-associated services. When it comes to marginalised communities, even the detection of HIV is not possible without prevention services, which establish initial contact with vulnerable people and offer friendly and low-threshold HIV testing services. This is why HIV prevention and harm reduction services – and particularly, outreach by community-led and community-based services – lay the essential ground for any HIV-related work in the community of PWUD. This guide aims to assist the community-led organisations in monitoring the core elements of HIV prevention and harm reduction work among PWUD and utilising CLM to ensure these services are relevantly focused, are of sufficient scale and acceptable quality to make a significant impact on the HIV epidemic and associated challenges.

Picture 1. The cascade of HIV Prevention, Care and Treatment Services for Key Populations (KPs) (schematised by the US funded Linkages project[1]). The scheme demonstrates that the initial engagement with KPs associated with HIV prevention programmes constitutes the foundation of access to any HIV services



[1] Quoted from: https://www.fhi360.org/projects/linkages-across-continuum-hiv-services-key-populations-affected-hiv-linkages Accessed on 5th December 2022.

2. What Services Are We Monitoring for People Who Use Drugs?

Community-led monitoring complements the standard or official monitoring efforts, which themselves may have deficiencies and may require specific attention of the affected communities as part of CLM. Although it is more common for CLM activities to focus on particular services or aspects of programmes, community-led organisations do engage in the broader analyses of the national or district programme architecture and may scrutinise the appropriateness of programme objectives and target populations, the sufficiency of coverage, the completeness of monitoring data[2], or the adequacy of funding allocations and funding distribution between various components of HIV and harm reduction interventions. Community monitors can assess the current funding situation and develop recommendations on necessary adjustments based on good international practice and available scientific and operational evidence. This is very important for the funding of complementary services, where lack of funding may lead to the loss of coverage due to low ability to offer what people feel they most need and decreasing retention rates, indicating intervention failure.

CLM approaches services and service delivery differently from the standard or official monitoring systems. In an ideal world, these two would complement each other or even integrate, but in reality, this transformation of approach to monitoring is far from complete. CLM intrinsically assumes that there are likely to be deficiencies in the way services are designed, focused and delivered that are best identified by those people who need those services. CLM aims to identify and remedy the deficiencies that can make services ineffective or useless, i.e., not responding to the essential public health challenges and/or the vital needs of the affected populations.

[2] Please refer to Annex 2 (General Approach to Monitoring HIV Interventions) for the outline of essential parameters of monitoring efforts, that may get into focus of attention of community leaders

2.1. The Key Dimensions of the Access to Services to Consider by CLM Implementers

The assessment and analysis of services can be structured using the Four "A"s Conceptual Framework. The following are the four areas of the framework that can be considered by CLM implementers with some of the questions that the CLM efforts could scrutinise and improve:

Availability: Availability refers to the presence and adequacy of prevention services, resources and interventions. It examines whether essential HIV prevention methods, such as access to condoms, PrEP, counselling, OST and testing services, are readily available within the community.

Accessibility: Accessibility focuses on the ease with which individuals and communities can access HIV prevention services. This dimension takes into account geographical proximity, transportation options, opening times, affordability, safety of the service environment, administrative accessibility, and awareness of services. Access to services should not be limited based on socio-demographic or other criteria such as age, sex/gender, sexual orientation, nationality, race or ethnic background, employment status or profession (including sex work), freedom restrictions, housing status, mental health conditions, pregnancy, or past/current drug use[3]. Ensuring that prevention services are easily accessible encourages higher utilisation and, in turn, contributes to reducing the spread of HIV.

Acceptability: Acceptability refers to the cultural, social and personal factors that influence people's willingness to engage with HIV prevention services. This dimension assesses whether the provided prevention services are culturally sensitive, respectful of diversity, and free from stigma and discrimination. Other relevant issues include confidentiality, privacy and informed consent. Ensuring acceptability is essential for reaching and engaging key populations effectively.

[3] WHO, UNODC, UNAIDS technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users., WHO, 2009, P.9. Available at: https://www.unodc.org/documents/hiv-aids/idu_target_setting_guide.pdf

Quality: Quality refers to the user's perception of service effectiveness, safety, and overall satisfaction with the prevention services provided. It scrutinises factors such as the competence of healthcare providers, waiting times, the ease of referral process, the adoption of a client-centred approach, and the overall experience of those using the services. Evaluating and improving the quality of HIV prevention services ensures that they are effective in reducing the risk of HIV transmission.

The guiding questions for exploring these four key areas are included in Annex 1. Exploring these and other areas may help CLM implementers identify some of the essential challenges that negatively affect the delivery and utilisation of services. It is essential though for the CLM efforts to continue beyond the identification of gaps and challenges into systematic advocacy and technical support efforts aimed at improving access to and quality of services. In order to advocate for and work on improvements, it is important to have some reference to good practice in harm reduction programming, which the communities will be aiming to achieve with the help of CLM, programme development and advocacy efforts.

2.2. Harm Reduction and HIV Interventions among PWUD

Harm reduction and HIV programmes for PWUD are mutually reinforcing combinations of multiple components and characteristics. The following table illustrates the range of HIV services for people who inject drugs (PWID), highlighting the general principles of effective service delivery, the essential and complementary services, and a range of management and support functions performed by service providers in collaboration with various stakeholders. Further in the chapter, we will consider aspects that may require the most attention from CLM implementers.

Table 1. The Key Principles and Components of HIV and Harm Reduction Work among PWID

General Principles and Fundamentals of Effectiveness	Recommended Combination of Services		Management and Support Functions	
	Essential Health Services to Prevent, Diagnose and Treat HIV, viral hepatitis and STIs	**Enabling Interventions and Complementary Services** (Enable access to services, protect human rights, satisfy basic needs, attract and retain clients)	**Strategic management**	**Provider level**
1. Community engagement and leadership 2. Community accountability 3. Safeguarding clients 4. Formative assessment and monitoring 5. Outreach strategy 6. Comprehensive case management 7. Service integration and referrals 8. Segmentation of clients 9. Marketing and demand generation	1. Needle and syringe programs (NSP) offering sterile injecting equipment, including water, cookers, filters, etc. 2. Reducing injection frequency / Ensuring access to and support of opioid substitution therapy (OST) 3. Overdose prevention and management (including Naloxone and drug checking[4]) 4. Prevention of sexual transmission (condoms and lubricants, STI services) 5. PrEP[5] for HIV 6. PEP of HIV and STI 7. Prevention of vertical transmission (HIV, syphilis and HBV) 8. HBV vaccination 9. Addressing chemsex 10. HIV testing and treatment 11. HIV-associated TB services 12. HBV and HCV testing and treatment 13. Generating knowledge, skills and behaviour change (IEC)	Enabling interventions: 1. Removing punitive laws, policies and practices 2. Reducing stigma and discrimination 3. Community empowerment 4. Addressing violence Broader health and complementary services: 1. Sexual and reproductive health (incl. conception and pregnancy care, contraception, cervical cancer services, safe abortion) 2. Mental health and psychosocial support services 3. Services to address problem substance use 4. TB services 5. Basic health care 6. Legal support 7. Livelihood development 8. Crisis response and humanitarian assistance	1. Strategic planning and budgeting 2. Resource mobilisation, Ensuring proper and effective use of resources 3. Ensuring access to medicines and other health-related products 4. Technology and human resource development 5. Monitoring, evaluation and research 6. Sub-recipient management and support 7. Structural interventions and advocacy	1. Uninterrupted service delivery 2. Supply management 3. Schedule and location of service delivery units 4. Human resource management 5. Costing services 6. Adequate policies and procedures regarding drug use by clients and staff 7. Protection of confidentiality 8. Safe working conditions 9. Protection of children and adolescents 10. Disposing of injecting instruments and medical waste 11. Ensuring support of local community and authorities

[4] Drug checking services enable people who use PAS to have their drugs chemically analysed, providing information on the content of the samples as well as advice, and, in some cases, counselling or brief interventions. Although WHO has not yet issued recommendations related to drug checking, drug checking services are among the most demanded harm reduction services and are currently available in more than 20 countries around the world. A growing number of studies have demonstrated the range of their utility. Please refer to Chapter 4.4 for more information on drug checking.

[5] PrEP (pre-exposure prophylaxis) of HIV infection is medicine that reduces your chances of getting HIV from sex or injecting drug use. When taken as prescribed, PrEP is highly effective for preventing HIV. PrEP pills reduce the risk of getting HIV by at least 74% when taken as prescribed. No significant health effects have been seen in people who are HIV-negative and have taken PrEP for up to 5 years.

2.2.1. Monitoring Needle and Syringe Programmes

CLM Focus: Needle and Syringe Programmes

Purpose: Ensure sufficient access to and quality of NSP

What to monitor:

- TWhether any restrictions exist on the quantity of distributed injecting instruments to satisfy the needs of clients.
- Whether needles and syringes with Low Dead Space[6] are utilised wherever accepted by people who inject drugs.
- Whether distributed injecting instruments satisfy the key demands of the target audience. These demands are based on the specifics of injecting practices prevalent in a given locality. CLM can monitor whether the needs of the target population and peculiarities of local injecting practice are taken into account in the development of technical specifications for the procurement of injecting instruments.
- Whether instruments that do not meet the requirements of clients and do not take into account peculiarities of the local drug scene and injecting practices are distributed.
- Whether clients are informed about the safety precautions during handling utilised injecting equipment.
- Whether NSP is easily accessible (opening hours, geographical proximity, transportation options, affordability).
- Whether clients' rights for confidentiality and privacy are respected.
- Whether NSP providers possess the required qualifications, knowledge, skills and attitudinal characteristics.

Please refer to the next chapter for an example of a CLM data collection tool for monitoring the spectrum and appropriateness of distributed harm reduction products. Please refer to Annex 4 for information on ensuring the appropriateness of distributed harm reduction products.

[6] Please refer to Annex 3 for a detailed consideration of dead space in injecting equipment.

2.2.2. Monitoring Opioid Substitution Treatment

CLM Focus: Opioid Substitution Treatment

Purpose: Ensure sufficient access to and effectiveness of OST

What to monitor:

- Whether the local standards of OST are conducive to sufficient access and effective treatment.
- Whether the actual services are compliant with the established procedures and standards.
- Whether the contents of IEC work and specific characteristics of information delivery and skills building support the achievement of medication delivery and reduction of HIV risk.
- Whether the service providers possess the required qualifications, knowledge, skills and attitudinal characteristics.
- Whether service delivery is flexible enough to allow for patient recruitment and retention (operating hours, take-home doses, requirements for entry, etc.)
- Whether the patients have access to complementary services, they require to be able to adhere to OST.
- Level of OST client satisfaction.

Other issues that can be subject to CLM monitoring of OST:

- Threshold: identifying requirements or practices that decrease service accessibility, including requirement for multiple forms, additional testing fees, inpatient hospital stays to begin treatment, etc.
- Delivery: Medicines permitted by law or regulation and restrictions on scale or service expansion resulting from unnecessarily restrictive regulations on medicine use, storage, or distribution, which may discourage OST service providers from seeking further expansion of service coverage.
- Appropriate therapeutic dose based on clinical indications and client satisfaction rather than on rigid regulations.
- Take-home doses: exploring whether practical compromise is in place between the client and provider perception of the optimal take-home period and monitoring procedures.
- Urine testing for illicit substances and penalties: making sure the patients are not excluded from services for illicit substance use and that such use is addressed through OST dose adjustment and other support.

Many of the challenges with OST relate to imperfections of the national regulations, which may need to be reformed or challenged through national coordination bodies. This requires concerted advocacy efforts of multiple stakeholders, including patient groups and practitioners. However, certain improvements are possible at the facility level and do not require revision of national-level policies. CLM data (e.g., client satisfaction survey data triangulated with clinical records) may be a powerful tool in negotiations with service providers regarding improvements.

2.2.3. Monitoring Service Quality and Client Satisfaction

Client satisfaction with services is the main measure of their relevance in the specific local and temporal context and many other aspects of service quality. Please refer to the next chapter for an example of a CLM data collection tool for monitoring data quality and client satisfaction levels.

CLM Focus: Monitoring Service Quality

Purpose: Ensure the provided services are of acceptable quality for the target population.

What to monitor:

- Availability of the service (consider availability of various complementary services as well as various specific components of each service, such as the full range of harm reduction commodities, gender-specific services, services and commodities essential for various sub-populations of clients such as opioid or stimulant users or people who use PAS to modify their sexual experience. Explore unsatisfied needs of clients that could be met with additional services or service modifications)
- Accessibility of the service (consider geographic/spatial, temporal, financial accessibility, admission requirements and the height of the threshold. Pay particular attention to any access restrictions and justifications/rationale for those)
- Acceptability of the service (consider whether various characteristics of the service and service delivery modalities correspond to the needs and preferences of various categories of clients)

- Other aspects of service quality not considered under the above categories, such as the client safeguarding and community accountability mechanisms integrated within the service delivery mechanism, capacity, qualifications, skills and attitudinal characteristics of service providers.
- Standards of service delivery. Do they cover all of the essential dimensions of the services? Do the providers comply with the standards?
- Contextual relevance of services. Are services tailored to address the peculiarities of the local drug scenes, or are they outdated?
- Whether services have a trauma-informed and client-centred approach.
- Whether services offer treatment for common comorbidities, such as wound care, drug dependence treatment, hepatitis C services, TB services, sexual and reproductive health services.
- Whether services respect clients' rights to confidentiality and privacy.
- Level of client satisfaction. Satisfaction of the clients with the service takes priority in establishing the service quality over the perceptions of providers. Regular client satisfaction assessments allow for measuring progress in service improvement.

For example, CLM can investigate how easy it is for women who use drugs to access harm reduction services. These services are usually designed more for men, and this can mean that women's specific needs are often not properly recognised and addressed. For instance, harm reduction programmes may not ensure the safety and privacy of women. They might also lack support or referrals for important services like sexual and reproductive health, care for pregnant women or childcare assistance. The staff in these programmes may not have the necessary training to offer the right help to women who use drugs, including sex workers and transwomen, many of whom have faced gender-based violence. CLM can look into all of these aspects to see if harm reduction services are truly accessible and responsive to the needs of women.

CLM can integrate human rights considerations in various ways. CLM can evaluate the provision of HIV prevention services to ensure they are free from discrimination, stigma and biases. CLM can also examine the respect for privacy and confidentiality during service delivery, upholding individuals' rights to keep their HIV status confidential and verify informed consent for medical procedures.

For example, CLM may include questions such as whether respondents have encountered discrimination based on their drug use in the past year, experienced denied medical care due to drug use or HIV status, suffered confidentiality breaches at healthcare facilities or felt unwelcome at services because of their drug use.

2.2.4. Monitoring the Optimal Combination of Services

It is important to acknowledge that the optimal combination of services is an inevitable compromise between the interests of public health and the essential needs of the affected communities. To be effective in achieving the ultimate public health targets, the offered combination of services should include not only services designed to achieve the primary HIV prevention and care targets or other associated public health objectives but also a range of complementary services that are designed to enable access to services, protect human rights, satisfy the essential humanitarian needs of the clients, as well as generate demand, attract and retain the affected communities in health programmes.

For services for people who use drugs, a key harm reduction principle is "meeting people where they are" and making therapeutic alliance with people by providing them services they have identified as important.

These enabling and complementary services directly influence the achievement of primary public health objectives, as the satisfaction of basic humanitarian needs is necessary for ensuring sufficient coverage of public health interventions. The additional services also directly contribute to improvements in the quality of life of marginalised and disadvantaged communities and attain essential human rights, thus removing significant obstacles to access to public health programmes.

Typology of Service Combinations: Balance of Public Health Priorities, Client Needs and Available Funding

- **Minimum** (usually defined by availability of funding and other resources).
- **Basic** (services that are required to establish contact with clients and maintain their interest in the programme).
- **Essential/Vital/Core** (services that are required to achieve public health objectives and/or respond to the vital needs of the clients – balance of public health and user perspective).
- **Comprehensive** – ideal service combination (package) that responds to all needs of clients and ensures the achievement of all public health objectives.
- **Optimal** – usually combines the essential services with a certain number of complementary ones, which can be afforded by the implementing agency in a given context.

CLM Focus: Combination of Services

A possible CLM task is the regular validation of the combination of services offered by HIV and harm reduction programmes. This can be implemented by drawing an inventory of existing services with the analysis of reasons for the inclusion of each of the components in the offered combination. The current inventory is then compared to the aspired service combination based on the actual public health and community needs in the given locality.

When regularly collected, these data can be used to measure the development towards a more comprehensive service combination, build linkages and referrals between unlinked services operating in the area and utilise the arguments in advocacy and negotiations with stakeholders aimed to improve the situation. This is an example of CLM looking beyond specific services or components and scrutinising the overall architecture of the programmes. Specific combinations of two or more services may be of particular interest to the local PWUD community.

Examples of specific questions are whether HIV or HCV diagnosis and treatment services are available to OST patients at a given facility or geographic location, whether OST programmes are offering needles, syringes and other injecting paraphernalia to their patients (or whether those are easily available in the proximity from another harm reduction provider), or whether human rights protection measures are in place for clients of harm reduction services (e.g., whether harm reduction drop-in centres employ lawyers to provide legal advice and protection to their clients).

whether those are easily available in the proximity from another harm reduction provider), or whether human rights protection measures are in place for clients of harm reduction services (e.g., whether harm reduction drop-in centres employ lawyers to provide legal advice and protection to their clients).

2.2.5. Assessing Service Providers

Various types of organisations can deliver HIV services to key populations. State-run healthcare facilities have the capacity to offer a broad spectrum of services, but they often lack mechanisms to reach marginalised communities effectively. To bridge this gap, collaboration with community-based organisations with effective outreach methods is crucial. These organisations should employ members from the targeted communities to establish contact and penetrate the social networks of these marginalised groups.

CLM can be instrumental in assessing service providers by promoting these collaborative efforts and emphasising the importance of community engagement to improve access, quality of care and support for key populations.

CLM Focus: Service Providers

CLM Agenda: Types of Service Providers and the Adequacy of the Deployed Teams

Purpose: Ensure services are delivered by trusted providers who employ peer workers for the essential frontline functions.
What to monitor:

- Whether the type of provider is adequate for the performed tasks and the local context.
- Whether the provider ensures the optimal level of community engagement in the given circumstances.
- Whether the provider employs peer workers for the essential frontline functions, such as outreach, case management, service marketing and client education.
- Level of client satisfaction with personnel performing various functions related to service delivery.

Please refer to the INPUD (International Network of People who Use Drugs) qualitative study on Key Populations' Values and Preferences for HIV, Hepatitis and STI Services[7] for detailed analysis and rationale for addressing values and preferences of PWUD to improve access to essential interventions. The findings of the study influenced the revised WHO Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations.[8]

[7] Available at: https://inpud.net/wp-content/uploads/2022/01/INPUD-WHO-Values-Preferences-Study-Report.pdf
[8] Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO.

2.2.6. Monitoring Representation

The extent of representation of people who use drugs in decision-making structures at various levels is another area for community-led monitoring. Multiple benefits associated with such representation are discussed in relevant publications by the Global Fund and other international organisations. The Global Fund, PEPFAR, other donors and governments and professional organisations assigned communities significant roles in decision making, planning and implementation of programmes. This strengthens and additionally legitimises the communities in their advocacy to participate in stakeholder coordination and decision-making bodies. One area that can become complex to assess in CLM is the quality of community representation. There are subtle distinctions between perceived, claimed, and actual representation. Even the direction of representation is sometimes unclear – whether the leaders of the community represent its interests from the bottom up, building a system of representation that is attentive to the actual needs of affected people on the ground, or whether the leaders use the system of representation to translate stakeholder positions and their own agendas to their representatives in the field. Both representation streams should be well balanced, and effective bidirectional communication between various levels of the representation structure is important. A good representation system should also involve proportional representation of various specific sub-populations within KPs, such as appropriate gender and age quotas, as well as segments of the population that have significantly different vulnerability and other characteristics, e.g., users of opioids and stimulants, people who inject drugs (PWID) who are OST patients, etc.

3. How Do We Monitor Services for People Who Use Drugs?

CLM relies on a range of data sources and tools, including client satisfaction surveys, operational protocols that establish service standards, service delivery statistics (compared to the local key population estimates), structured interviews with both service providers and clients, structured observations of service delivery, routine data collected through various client feedback mechanisms, and the documentation of capacity development efforts aimed at improving service quality.

3.1. CLM Data Collection Tools: Service Quality and Client Satisfaction

DATA COLLECTION RECOMMENDATIONS FOR MONITORING SERVICE QUALITY AND CLIENT SATISFACTION

CLM relies on a range of data sources and tools, including client satisfaction surveys, operational protocols that establish service standards, service delivery statistics (compared to the local key population estimates), structured interviews with both service providers and clients, structured observations of service delivery, routine data collected through various client feedback mechanisms, and the documentation of capacity development efforts aimed at improving service quality.

Aspects of service delivery that need to be explored to determine client satisfaction and service quality include:

- The spectrum of essential and complementary services and how it corresponds to the actual needs of the clients.
- The effectiveness of referral systems to ensure access to complementary services.
- The spectrum of distributed HIV prevention and harm reduction commodities and other health products.
- Appropriateness of information provided to clients regarding their challenges, conditions, vulnerabilities and risks and specific guidance to address or overcome those.

- Ability to accommodate specific needs of various sub-populations within the target clientele, including gender and age groups, users of specific types of substances, etc.
- Sensitivity of service providers to stigma, psychological/emotional vulnerability of clients.
- Ability to identify and address compromised mental health due to a wide variety of additional stressors, including criminalisation, stigma, complex relationships with law enforcement and comorbidities.
- Ability to accommodate hectic schedules of the clients or schedules that do not fit common daily routines of most people and services.
- Ability to identify and respond to common comorbidities requiring coordinated attention of several specialists, e.g., drug treatment specialist, infectious disease specialist, surgeon, dermatologist, psychologist, psychiatrist, sexual and reproductive health specialist, etc.
- Ability to offer support related to cooccurring social or legal challenges related to housing, nutrition, hygiene and childcare.
- Adequacy of confidentiality (or anonymity) requirements linked to the **criminalisation of personal choices and lifestyles**, protection against disclosure of socially disapproved behaviours or health status information to partners, relatives and social institutions (e.g., the police, non-health staff in prisons, etc.). Mechanisms to protect clients from arrest or police harassment.

Communities can use the following sample script to design a desired combination of services or a perfect programme. Then, these preferred parameters can become advocacy targets and milestones that can be utilised in monitoring.

WHAT DO WE NEED TO KNOW IN ORDER TO INFORM EFFECTIVE HIV AND HARM REDUCTION SERVICES?

Who are we (what is our identity)? Are there different groups or communities within our aggregate larger community (also called by healthcare professionals a key population)?
How many of us are at risk?
What are the risk factors (Why exactly are we at risk, including structural causes of risk such as laws and policies impeding access to or delivery of HIV services)?
Where to find us to educate and engage in the interventions?
How to attract us to services?
What do we value and what are our priority needs as we perceive them?
How the risks of HIV transmission can be reduced in our communities? What do we need to know? How should that knowledge be expressed and communicated for us to accept it?
What skills do we need? How do we need to modify our behaviours? What specific practices should we avoid? Modify? Introduce?
What health products or other commodities do we need to be able to protect ourselves and our partners?

WHAT LEVEL OF DETAIL DO WE NEED TO UNDERSTAND THE SPECIFIC RISKS AND DEVELOP PREVENTION SOLUTIONS?

What substances do we use for injecting? How long does the psychoactive effect last? How many times do we inject per day? How much of the substance do we fill into the syringe each time? Where on the body do we inject? What thickness of a needle do we need/prefer? How long should it be? What other properties of a syringe are important? Do we use water to dissolve the substance that we inject?Do we share syringes/needles/water/filters/cookers/alcohol swabs/stirring tools/syringes or other vessels to mix/prepare/distribute the substances? Do we have sex under the influence of psychoactive substances? Do we have sex when sober? Do we use condoms? Lubricants? How many sexual partners do we have? How often do we test for HIV? How many of us are HIV positive? Do all HIV-positive people access ART? Do we know about the benefits of Pre-Exposure Prophylaxis (PrEP)? How many of us use PrEP? Contemplate? What else do we need to know to decide on the initiation of ART or PrEP? Do we have access to naloxone? Do we know how to use it and how to act in case of overdose in the community? Do we have access to drug checking (even if it is a simple fentanyl strip)?

3.2. CLM Data Collection Tools: Checklist of Harm Reduction Commodities

List of essential harm reduction commodities that should be made available and easily accessible by HIV prevention programmes depending on the local drug scene

- Syringes
- Needles
- Sterile water
- Filters
- Tourniquets
- Naloxone (effective antidote against opioid overdoses)
- Fentanyl strips (rapid tests for detection of fentanyl in samples of psychoactive substances) (for countries where fentanyl is present)
- Condoms and lube (depending on the specific needs of certain communities)
- Bandages, antiseptic ointments and other medicines depending on the prevalence of specific conditions affecting veins, etc.

Complementary commodities and services

- Accessibility of HIV testing with relevant counselling and follow-up support depending on the results
- Accessibility of ART for clients testing positive for HIV infection
- Accessibility of PrEP and required preparatory procedures (testing for HIV infection and medical assessment of liver and kidney function)
- Accessibility of HCV diagnostics and treatment
- Accessibility of TB diagnostics and treatment

3.3. CLM Data Collection Tools: Harm Reduction Communication

SAMPLE COMMUNICATION PLAN FOR HARM REDUCTION WORK WITH PWUD

- Psychoactive substances, their effects and drug interactions. Measures to reduce harms associated with specific substances and modes of administration. Use of sterile injecting equipment. Prevention of sharing. OST. Overdose and available antidotes and overdose prevention and management methods. HIV/HCV/HBV/TB testing. PrEP and PEP. HBV vaccination.
- Equipment and paraphernalia utilised in preparation, sharing and using of psychoactive substances. Risks associated with the use of various equipment. Preferred types of equipment and procedures for safer utilisation.

Includes consultations with clients regarding the preferred types and characteristics of equipment and paraphernalia and the reasons for preferences, as well as the level of satisfaction with the commodities distributed by HIV prevention programmes, followed by the development of communication strategies to address harmful myths and promote alternative utilisation strategies. Consider offering incentives for participation in client satisfaction surveys and other data collection activities.

4. What Happens After CLM Data Collection?

After the data collection phase of CLM, the obtained information is analysed. Through analysis, the data derived from CLM transforms into supporting evidence.

This evidence is instrumental in recognising and executing solutions for improving programme and service delivery and in providing guidance for advocacy actions.

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Results dissemination plays a key role in ensuring that the findings are effectively communicated as evidence to decision and policy makers. This communication serves as a foundation for further programme development and improvement, as well as addressing advocacy needs. Various options can be explored for disseminating these results, including organising roundtable discussions, engaging in consultations, delivering presentations, and distributing a printed version of the report. Additionally, having a hard copy of a brief summary, which highlights key results, can be useful in conveying critical information to a broader audience.

Advocacy actions are also a vital step of the CLM process, as they play a central role in driving positive change. Advocacy goals often involve change at multiple levels, ranging from national to regional and local, and may encompass various aspects, such as policy reform, alterations in service delivery mechanisms, shifts in decision-making processes, or changes in the attitudes and behaviours of personnel involved in service provision. This advocacy work is often done by revisiting the clinics, forming Community Consultative Groups, or utilising existing forums and structures where policies and decisions are made. Through advocacy, the findings of CLM can lead to positive responses, such as more outreach (which, in itself, is not a service but a range of strategies and activities designed to identify, engage and retain clients in any of the health and social programmes) and more demand generation (which can be achieved through service promotion).The CLM data collection can serve as a potent advocacy tool itself, influencing the behaviour and attitudes of service providers who are aware of the ongoing monitoring activities in their facilities.

The final step is to monitor the changes initiated as a result of the CLM process. Even if the initial challenge has been addressed and overcome, it is crucial to ensure the continuity of the achieved results. Sometimes, policy changes may occur, but the actual practices on the ground remain unaffected, or certain personnel and sites may resist or reject the changes.

This is precisely why ongoing monitoring is vital. It not only helps in preventing a rollback situation where all the hard work and resources invested go to waste but also ensures that the positive changes are sustained and have a lasting impact.

5. Why Is CLM a Good Approach to Improve Services for PWUD

The CLM concept is based on the recognition of the unique role of the communities in ensuring access to and quality of healthcare services. Communities have unique attributes that can be nurtured and tapped to improve planning and health service delivery at community level, including the capacity to advocate effectively, play the "watchdog" role, and utilise experiences to advise on what works and what does not. CLM does not replace the routine monitoring systems but looks at the aspects of service design, funding and delivery that are the most essential from the community perspective and may not receive sufficient attention in the mainstream monitoring systems. While conventional monitoring and evaluation methods may provide statistics and information about services, CLM goes beyond the surface to gather complementary data on the user experience in a systematic way.

This approach provides a qualitative perspective, allowing a deep understanding of the issues faced by PWUD. CLM is targeted to specific populations and involves the affected community directly; consequently, it provides valuable insights into the specific needs and concerns of PWUD. The Global Fund defines CLM as an accountability mechanism that uses an independently structured and planned process designed and led by equipped, trained and paid members of community-led organisations of affected communities to systematically and routinely collect and analyse quantitative and qualitative data from health service delivery sites (i.e., facility-based and beyond) and affected communities either for a specific disease component (i.e., HIV, HIV/TB, TB, malaria) or broader primary health care[9].

[9] RSSH Info Note 2022 https://www.theglobalfund.org/en/applying-for-funding/design-and-submit-funding-requests/applicant-guidance-materials/

There are five key conditions required for effective community-led monitoring, namely[10]:

- It should be conducted **by communities;**
- It should be conducted **routinely** and not as a one-off activity;
- It should be conducted **rigorously** in regard to the collection and treatment of data, which should be verifiable, reliable and collected under human rights principles that ensure informed consent, confidentiality, security and no harm;
- It should be **independent** of government systems or sponsorship, and the data ownership should belong to the communities;
- It should be **actionable** and lead to advocacy wins that improve services from the ground up. **Identification of problems is not the ultimate goal – it is necessary to move on to solution.**

By allowing the communities to systematically obtain, process, analyse and utilise data, CLM takes community engagement to a new level. The cases presented by communities gain the required weight in the stakeholder dialogue as they become grounded in the systematic collection and analysis of structured programme-related information. This further legitimises the crucial community contribution to:

- Understanding the drug scene
- Understanding the demand, defining and packaging services
- Penetrating social networks of PWID and nurturing rapport
- Developing an effective outreach and retention strategy
- Defining a communication strategy, using the grapevine
- Challenging and changing behavioural norms
- Mobilising support for retention and adherence
- Legitimising and leading the policy and advocacy action and
- Community-led monitoring efforts.

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[10] UNAIDS CLM guidance: https://www.unaids.org/en/resources/documents/2021/establishing-community-led-monitoring-hiv-services

Systematic engagement in these areas supported by reliable monitoring data allows the communities to achieve greater and more substantive levels of engagement, moving from the basic engagement levels, such as providing feedback on services or involvement in outreach and service delivery (peer models), to more advanced involvement in programme development, management, coordination and governance (including membership and leadership in advisory and coordination bodies such as Country Coordination Mechanism (CCM). CLM efforts are collaborative and intended to engage multiple stakeholders to co-create and implement solutions instead of assigning blame.

5.1. The CLM Sequence

The goal of CLM is to ensure universal access of beneficiaries to high-quality services. Organisations that plan and implement CLM activities must clearly define agendas for improving access to services and quality of services in a defined geographic area, set clear and achievable targets, and thoroughly plan the activities required to achieve these goals. The complete sequence of practical steps that may be required to engage, plan and implement effective CLM includes:

- A well-defined community and a detailed geographic scope. It is essential to understand the internal architecture of the community and its heterogeneity to identify any underrepresented segments of the community that require special support to ensure their engagement and meaningful participation. Ideally, the CLM team's composition will reflect the community's structural diversity.
- Through literature review (local and international) and in-depth consultations with HIV and harm reduction practitioners, we build our understanding of how similar interventions are implemented in other contexts to shape our own interventions. This includes:
  - the nature of the interventions/services,
  - the available/optimal/state-of-the-art/potential/promising delivery mechanisms,
  - available evidence, both scientific (obtained through appropriately designed

- studies) and operational (gained – preferably first-hand or by well-recognised and reliable partners - from extensive, carefully monitored and thoroughly documented experience),
    - common challenges and solutions.
- Full assessment of the service we monitor: availability, accessibility, acceptability and quality. This requires effective data collection tools that can later be adjusted and finalised for routine monitoring. This monitoring will identify essential aspects of the service that will become a focus of further systematic monitoring and the desired improvements.
- Develop a plan for routine monitoring, including staffing, budgeting, data collection and management, production, presentation and further use of findings and recommendations.
- Creation and adjustment of data collection and management tools.
- Implementation of the monitoring plan. Analysis of the results. Formulation of findings and development of recommendations.
- Finalisation of analysis. Production of findings and recommendations for specific purposes. Implementation of advocacy agenda.
- The advocacy plan includes identifying the desired specific outcomes, stakeholders/partners (allies/influencers and targets/influenced), resources and processes to access the required resources, links to monitoring mechanisms and further reassessment of the situation and progress with service improvement.
- Partnership arrangements for further service improvements involve extensive consultations and negotiations with various stakeholders (inventory created through brainstorming and snowball sampling), agreements and memoranda, gaining legitimacy, joint planning and distribution of labour, access to data and data security and restrictions and confidentiality arrangements.

5.2. CLM Outcomes

Any CLM efforts will be void if they do not lead to specific service improvements. These improvements can relate to a variety of aspects of service access and delivery, including multiple back-up functions and preparatory processes enabling effective delivery of services. Below are some examples related to harm reduction interventions:

Functional area	CLM Outcome	Examples of specific improvements
Procurement and supply of harm reduction commodities	Uninterrupted supply of commodities in sufficient quantities according to the needs	Reduction in the frequency/duration of stockouts of key commodities and medication, e.g., needles and syringes, other injecting paraphernalia, OST, condoms and lubricants, and PrEP
	Optimal spectrum of the offered harm reduction commodities	Commodities and their specific characteristics are defined based on identified needs of the target population. The facility offers a variety of harm reduction commodities, including OST, NSP, condoms and lubricants, PrEP, PEP, HIV/HCV/HBV testing, HBV vaccination and naloxone
Acceptable service delivery arrangements at the facility level	Improved conditions at service delivery facility (e.g., clinic or drop-in centre)	The facility has introduced specific measures to protect privacy and confidentiality of clients/patients – specifically related to protection of people living with or affected by the diseases
	Reduced waiting times	Opening hours at the facility are adjusted to accommodate the daily schedules of PWUD
	Reduced facility staff lateness and absenteeism	Staff lateness and absenteeism are addressed in facility operating procedures and are monitored and acted upon by the management
Human resources at service delivery facilities	Improved staff competencies	Facility staff trained in the essential competencies such as inclusivity and stigma-free attitude. These aspects are addressed in performance management procedures and professional supervision.
Rapport with the target communities	Improved community trust in service providers, service literacy, empowerment and engagement with service providers	Effective feedback mechanisms are introduced at the facility level – feedback is proactively sought, encouraged, processed and the issues raised by the clients/patients are timely and satisfactorily addressed

Outreach and marketing of services	Improved outreach strategy aligned with the comprehensive assessments of needs	The underserved cohorts of clients are identified and engaged through a tailored outreach mechanism and a balanced service combination, which includes complementary services responding to the essential needs of the clients
Regulatory environment	Improved regulations are more conducive to quality service delivery and service access by underserved communities	Adequate allowances for possession of PAS for personal consumption to prevent the criminalisation of PWUD and intervention of law enforcement impeding access to harm reduction services. Possession of injecting paraphernalia is not utilised as indirect evidence of illicit substance use. Justified take-home doses of opioid agonist medicines allow the patients to effectively fulfil their social functions
Equitable access	Improved access to service for underserved communities	Specific measures in place to ensure access by population groups with special needs and requirements (such as the need for specific health or social services, heightened confidentiality requirements, or specific physical access restrictions)
Funding allocation	Improved relevance of funding allocations	Services prioritised by the target communities are prioritised in funding allocations

6. Core Harm Reduction Services

6.1. Needle and Syringe Programmes

Needle and syringe programmes (NSP) are considered the single most important HIV prevention strategy for people who inject drugs. They can significantly reduce HIV transmission and acquisition related to injecting drug use while offering a range of additional benefits and linking people to complementary services. The purpose of NSP and integrated communication and skills-building activities is to ensure **safer use of injecting equipment** and access to prevention commodities through direct distribution and social marketing, as well as to facilitate the withdrawal of used instruments from circulation.

Ensuring access to sterile injecting equipment reduces the likelihood of its shared use, thus resulting in statistical reduction of the likelihood of HIV transmission during injecting drug use. UN has set a target of distributing ~200 clean needles per person injecting per year. In addition to needles and syringes, WHO[11] also recommends the distribution of other injecting paraphernalia, such as sterile water, alcohol swabs, filters, tourniquets, cookers for preparing injectable solutions, and acidifiers that increase the solubility of some psychoactive substances. Global AIDS Strategy 2021-2026[12] has set a target of 30% of services to be delivered by community-led organisations.

Harm reduction guidance from Global Fund states that NSPs can include a broad range of services, including the provision of basic medical assistance such as managing wounds and serving as a link to treatment for drug dependency, HIV care, support and treatment, HCV and TB diagnosis and treatment, PrEP, and distribution of self-tests, as well as other medical, psychological, social or legal services. Distribution of injecting equipment should be accompanied by access to information, particularly offering clarifications regarding the risks associated with certain injecting practices as well as the advantages of using alternative (non-injecting) modes of administration and injecting instruments such as low dead space syringes and needles.

[11] Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations – 2016 update. Geneva: World Health Organization; 2016. pp.32,70.
[12] UNAIDS. 2021.Global AIDS Strategy 2021-2026. Available at: https://www.unaids.org/sites/default/files/media_asset/global-AIDS-strategy-2021-2026_en.pdf.

Rigid requirements regarding the exchange of syringes and needles (requiring receipt of used needles in order to distribute sterile ones) may significantly reduce the programme's effectiveness.

Distribution, rather than exchange, is prioritised for HIV prevention, while the disposal of used equipment can be promoted and organised separately.

6.2. Opioid Substitution Therapy

Opioid substitution therapy, also known as opioid agonist maintenance treatment or opioid agonist treatment, is considered an essential intervention for people who are using heroin or other opioids both for its HIV prevention benefits and for its effects in increasing adherence to HIV treatment, reducing overdose, and other health and social benefits.

Access to OST reduces injection of and craving for opioids, reducing the likelihood of HIV transmission.

In addition, OST has been shown to improve social and family function, improve adherence to HIV treatment, and can be integrated with other important HIV prevention and health services, including PrEP, sexual and reproductive health and TB services. Punishment or expulsion from OST programmes for the use of opioids or other drugs decreases programme reach, and dose adjustment or additional support should be used instead.

6.3. Other Types of Treatment of Substance Use Disorders (SUD)

Apart from OST, other services can be offered for substance use disorders. These include inpatient detoxification, outpatient drug dependence treatment, inpatient short-term treatment, inpatient or residential long-term treatment, peer-based support groups (such as 12-step Narcotics Anonymous groups), and brief interventions delivered in non-specialist settings. While not recommended for HIV prevention by WHO or supported by the Global Fund to Fight AIDS, TB and Malaria, these can be important services to improve the quality of life of PWUD. Organisations aimed at satisfying the needs and protecting the rights of PWUD often find opportunities to deliver these services to their clients. However, these services are usually funded from sources not meant for HIV prevention and care.

Compulsory drug detention for the purposes of treatment or rehabilitation is unacceptable. In 2012, twelve UN agencies joined to call for the closure of such facilities and to urge countries not to utilise them for drug-dependent people and instead to ensure that people who require health services can access those in the community settings voluntarily[13].

CLM can play an important role in the documentation of human rights abuses and other issues facing patients of rehabilitation and treatment centres, raising these issues with the owners and managers as well as with governmental agencies regulating the delivery of services to PWUD and advocating for the required improvements.

6.4. Prevention and Management of Overdose

Opioid overdose is the greatest cause of mortality among PWID. Opioid overdose is both preventable and, if witnessed, treatable. OST is an effective prevention method among people dependent on opioids. Opioid overdose is treatable by respiratory support and via the short-acting opioid antagonist **Naloxone**, which is safe, non-abusable, easily administered and inexpensive. WHO recommends the availability of Naloxone to all those likely to witness an overdose, including people who inject drugs, their families and peers. Evaluation of peer availability of Naloxone and lack of police interference or punishment for its use is an area of importance for CLM, as it has been shown that both of these factors are integral to the success of harm reduction strategies.

Overdose and acute intoxication are also significant risk factors for users of non-opioid PAS, non-injecting users and people who use PAS in recreational contexts. For non-opioid users, drug checking is the most significant overdose prevention intervention.

[13] https://digitallibrary.un.org/record/3950265?ln=en

6.5. Drug Checking

Drug-checking services provide people who use drugs with chemical analysis of their drugs, offering information on their chemical content, advice, and, sometimes, counselling or brief interventions. The sites at which testing occurs include drop-in services with fixed laboratories, where individuals and organisations can submit drugs for testing (with results days later), and mobile laboratories at festivals, clubs, or drug consumption rooms, which provide almost immediate results.

Various types of drug-checking technologies include colorimetric reagents, Fourier transform infrared spectrometry, high-performance liquid chromatography (HPLC), gas chromatography and fentanyl strips. Currently, there is no formal WHO guidance on drug checking, but this intervention has been successfully implemented in more than 20 countries. Both opioid and non-opioid users can benefit from drug checking.

6.6. Decriminalisation of Drug Use

Decriminalisation of drug use and possession of injecting equipment for personal use is important for the development and scaleup of harm reduction programmes, as well as for any significant expansion of access to HIV treatment for PWUD. Even without changes in law, the use of law enforcement discretion to not arrest or harass participants in harm reduction education or services has been implemented in many countries. Harm reduction education and services for recreational users contribute to a more nuanced and objective understanding of substance use and associated phenomena among healthcare specialists, law enforcement personnel and the public, thus forming a more appropriate societal attitude and enabling legislative improvements required to achieve decriminalisation of substance users, thus removing one of the most significant barriers of access to services for PWUD.

6.7. PWID vs PWUD. Is it worth it to target non-injecting users with HIV and harm reduction services?

The scaleup of harm reduction services has been supported primarily through HIV prevention funding, with services focused on reducing the risk of infection for people who inject drugs. PWID are a key population most affected by HIV. Many of the funding agencies and organisations supporting HIV interventions limited their programmes for PWUD to those who use drugs by injecting.

Focusing HIV prevention efforts on key populations (KPs) disproportionately impacted by HIV is most effective when HIV infections among KPs represent a significant share of infections. This is particularly true for people who inject drugs since HIV can spread quickly if sterile injecting equipment is unavailable. Waiting until HIV becomes more generalised is a missed opportunity. It is also important to address the entry of new people into the population of those vulnerable to HIV. A large proportion of these are young people experimenting with psychoactive substances and exploring their sexuality.

Picture 3. Non-injecting use of heroin

Many psychoactive substances can be administered through various modes. One of the objectives of harm reduction interventions is to prevent the transition to injecting use or to promote non-injecting use of injectable substances among those who currently use by injecting.
Photography: © Slava Kushakov

Expanding harm reduction work to address other than injecting drug use can also help to reduce risk, either by preventing transition to injecting or addressing combinations of drug use and sex that increase vulnerability to HIV. Other modes of administering drugs include smoking, snorting or swallowing.

HIV prevention interventions for non-injecting drug users encompass a range of strategies to address their specific needs and reduce associated risks. These interventions include targeting experimenting users, including younger individuals at risk of transitioning to more problematic patterns of substance use. They involve harm reduction services, PrEP, online outreach, screening, referral to services and counselling for PWUD and their sexual partners. Additionally, interventions aim to prevent transitioning to injecting drug use, as it poses substantial health risks. They focus on the growing prevalence of **amphetamine-type stimulants** and **synthetic cathinones**, which increase the likelihood of **transition to injecting**[14], and stress harm reduction and overdose prevention. Encouraging safe sexual behaviours among non-injecting drug users, studying recreational drug scenes, and promoting inclusivity in modern nightlife culture are also integral to these interventions. Lastly, offering harm reduction information and services to people at the early stages of their drug use – before health deteriorates and other serious problems emerge – will bring significant benefits in prevention and care.

6.7.1. Services for Young People Who Use Drugs

Although HIV infection primarily concentrates among KPs (including people who inject drugs), experimenting with PAS and sex does put younger people at risk for HIV and other infections as well as at risk of transitioning to more problematic patterns of PAS use, such as injecting. We use the term experimenting young people to denote younger people who are starting to explore behavioural patterns that put them at heightened risk of HIV and other infections but do not necessarily identify themselves as members of the key population of PWID and are not attracted by social marketing and services targeting PWID.

[14] It should be noted that injecting use of PAS is not always preceded by non-injecting. A sizable share of PWUD in recreational contexts regularly or occasionally inject PAS or have experience of injecting. These experimental, occasional or regular injectors may require and need to be provided with all the services described in this chapter as relevant and as early as possible.

Experimenting young people include people who experiment with PAS in recreational and other contexts, as well as sexual partners of PWUD.

The approach to working with younger people who practice high-risk behaviours is radically different from the approach that prevails in most harm reduction programming for people who inject drugs. Problem and solution-focused information and service delivery may not be attractive to people at the pre-problematic phases in their lives despite the prevalence of high-risk behaviours. Young people or those early in their drug use (including experimenting young people exploring their sexuality) are not attracted by explicitly HIV or KP-focused services. Still, they can be attracted by information on areas of interest and by delivering services designed to reduce the risk and harm associated with pleasure-seeking behaviours.
Effective harm reduction services for young people should focus on aligning interventions with their values and preferences to engage experimenting individuals at an early stage of drug use. By building and maintaining rapport with these individuals, harm reduction services can prevent the transition to riskier behaviours, including injecting drug use, and reduce the risk of HIV infection and other related issues. To reach young people, culturally appropriate channels, including the Internet and social media, should be employed.
The design and branding of communication materials and service delivery platforms must also resonate with young people. Services should utilise harm reduction and HIV prevention commodities that are appealing and field-tested with the target audience. Additionally, monitoring the drug scene through studies of substance use and sexual practices can inform interventions and policy development, with field and online surveys serving as outreach channels. Where available, drug-checking services are highly valued among young people and should be incorporated into harm reduction programmes.

7. Service Integration and Complementary Services

7.1. Integration with HIV Detection, Care and Treatment Services

In addition to their direct prevention effect, HIV prevention and harm reduction programmes can play a significant role in ensuring access of key populations to HIV testing and treatment. Marginalised communities often delay seeking healthcare until they face acute phases of the disease. Enrolment in prevention programme facilitates access to HIV testing services. Many programmes also provide various support services that assist HIV-positive clients through treatment initiation and help with retention. For example, testing with rapid tests during outreach and within NSP by outreach workers and self-testing with the assistance of outreach workers has the potential to reach greater numbers of people than clinic-based testing services – particularly those unlikely to go to a facility for testing and those who are asymptomatic. Thus, integration of HIV testing with other harm reduction or HIV prevention services significantly improves HIV case finding and reaching the first 95 target of the HIV care cascade.

Antiretroviral treatment (ART) has a direct therapeutic effect and an indirect prevention effect. It directly influences the reduction in mortality and morbidity of PLHIV and reduces the likelihood of HIV transmission due to the reduced viral load. It is important to ensure access to women who use drugs, sexual partners of PWUD to Prevention of Mother-to-Child Transmission (PMTCT) services, and support to manage substance use during pregnancy, including access to OST for pregnant opioid users.

Organisation of HIV testing and follow-up enrolment of clients on ART or PrEP is an important area of CLM. CLM can focus on measuring the threshold of HIV testing and care services in the programme, confidentiality of patient records, stigmatisation among healthcare workers and other aspects of service delivery.

There are many useful resources developed to guide the implementation of community-led monitoring for care and treatment, including a range of resources developed by ITPC on treatment observatories and other community monitoring models[15].

7.2. PrEP

PrEP (pre-exposure prophylaxis) for HIV infection is a medicine that reduces your chances of getting HIV from sex or injecting drug use. When taken as prescribed, PrEP is highly effective for preventing HIV. PrEP is safe and reduces the risk of getting HIV from sex by about 99% when taken as prescribed. Although there is less information about how effective PrEP pills are among people who inject drugs, we know that PrEP pills reduce the risk of getting HIV by at least 74% when taken as prescribed. Currently, PrEP shots are not recommended for people who inject drugs. PrEP is safe. Taking PrEP pills only when you are at risk for getting HIV is known as "on-demand" PrEP.

PrEP should complement – rather than substitute – needle and syringe programming and OST as an HIV prevention measure. As in other services for people who use drugs, it is important to ensure protection against human rights threats and coercion. Protections should include confidentiality of patient data (including substance use) and no requirement of compulsory attendance at healthcare facilities.

As with other services for people who use drugs, the promotion and rollout of PrEP can benefit from the involvement of community-based and community-led organisations. CLM can assess barriers to PrEP and significant shortfalls in PrEP coverage of eligible populations, adherence challenges for people with chaotic lifestyles, risk of additional stigmatisation that would increase the burden of already highly stigmatised and marginalised communities, as well as limited satisfaction of more basic humanitarian needs such as shelter, food, and basic health care.

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[15] See e.g.:
https://stoptbpartnershiponeimpact.org/resources/Conceptual%20Framework/OneImpact%20CLM%20Conceptual%20and%20Implementation%20Framework%20FN.pdf
https://ritshidze.org.za/wp-content/uploads/2020/11/Ritshidze-Activist-Guide-2020-1.pdf
https://itpcglobal.org/wp-content/uploads/2022/07/Precision-in-a-Pandemic.pdf
https://itpcglobal.org/wp-content/uploads/2022/06/0618_C19Toolkit_Complete_03.pdf
https://itpcglobal.org/wp-content/uploads/2021/12/1205_ITPC_CLM_Design_FullReport06_compressed.pdf

Post exposure prophylaxis (PEP) is another important service that should be available to PWUD when they need it. Many PWUD are not aware of it or cannot access it. More advocacy is required to inform the community about this intervention to develop policies that focus on the importance of PEP for PWID and to work with law enforcement where PWID risk prosecution when seeking health services at public facilities.

7.3. Sexual and Reproductive Health Services (Preventing Sexual Transmission of HIV)

In countries with concentrated HIV epidemics associated with injecting drug use, sexual transmission of HIV from PWID to their sexual partners is one of the most significant channels of HIV acquisition by people without a history of injecting drug use. Ensuring access to prevention commodities such as condoms and lubricants by direct distribution or social marketing accompanied by promoting their use and forming motivation and necessary skills reduces the likelihood of unsafe behaviour and associated risk of HIV transmission. Distribution of condoms and relevant IEC work should be combined with utilising the prevention opportunities of ART and PrEP, as well as with other forms of targeted prevention work among PLHIV, who play a decisive role in preventing further transmission of the virus. STI diagnostics and treatment services are also essential in HIV prevention programmes, as acute sexually transmitted infections increase the likelihood of HIV transmission and acquisition during sexual contact.

Different segments of key populations may have varying sexual and reproductive health needs. CLM can contribute to the verification of sexual and reproductive health (SRH) and other needs of various segments within key populations and produce recommendations for adjusting the offered combinations of services and commodities.

7.4. Communication in HIV and Harm Reduction Work

Sufficiently deep understanding by PWUD of HIV transmission risks related to injecting drug use and unsafe sexual practices, as well as effective HIV prevention measures, is a crucial factor in reducing the incidence of unsafe injecting and other practices related to preparation, transportation and distribution of psychoactive substances.

Information and education work is more effective when, in addition to raising awareness, it also includes activities aimed at the development of skills required for safer behaviour. The effectiveness of this work further increases when it is combined with a simultaneous supply of sterile injecting instruments and other required prevention commodities. Information, education and motivation work, when properly organised and compliant with the essential quality and management standards, also facilitates timely initiation of HIV treatment as well as reduction in PWUD mortality (including overdose-related mortality).

The motivational element of Information, Education and Communication (IEC) work is important in the promotion and ensuring the effectiveness of treatment, including opioid agonist treatment and antiretroviral treatment.

Please refer to Chapter 3 for an example of a CLM data collection tool related to harm reduction communication and to Annex 5 for information about the possible spectrum of topics covered in IEC work, as well as the methods of IEC work.

7.5. Other Complementary Services

In addition to essential interventions described earlier, complementary services recommended by WHO and other international organisations[16] include:

Prevention, vaccination, diagnosis and treatment of viral hepatitis. Viral hepatitis, primarily B and C, adversely affects the health of PWUD and reduces the effectiveness of their participation in prevention and treatment programmes. In particular, hepatitis and HIV co-infection is associated with faster progression of liver disease and mortality among people with viral hepatitis B and C. WHO recommends treatment of all people with active HCV infection, regardless of whether they are actively using drugs, and supports the delivery of treatment in non-specialised settings including prisons and harm reduction services.

[16] WHO, UNODC, UNAIDS technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users., WHO, 2009. Available at: https://www.unodc.org/documents/hiv-aids/idu_target_setting_guide.pdf.
Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations – 2016 update. Geneva: World Health Organization; 2016.
Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO.

Prevention, diagnosis and treatment of tuberculosis.
PWUD, especially PLHIV, are at increased risk of contracting TB and developing the disease. WHO recommends ensuring that PWUD are aware of these risks and that screening and testing, as well as isoniazid preventive treatment for HIV-positive PWUD with inactive TB and treatment of active TB are available for those who are eligible for such treatment. The main treatment for TB is to take antibiotics for at least 6 months, but if TB spreads to critical areas such as the brain and spinal cord, individuals may also require steroid medication. There is also a possibility of interaction between OST and TB medication, and adjustment to the OST dose during TB treatment may be necessary. The dose will then need to be reduced at the end of TB treatment, or the person may overdose. WHO recommends close cooperation between TB clinics and prevention programmes for PWUD, including OST services, and ensuring unimpeded access of PWUD to treatment at such facilities.

Psychosocial support and mental health services.
The delivery of required psychosocial support, most importantly, support by trained peers, i.e., members of the target population, is of paramount importance both in HIV prevention programmes and in the delivery of care, support and treatment for PLHIV and OST patients, as well as HIV testing services.

7.6. Structural Interventions

Structural or enabling interventions, which are considered by WHO[17] to be essential for impact of HIV services, are another important area for CLM. These are designed to influence structural factors affecting the risk of HIV transmission and intervention effectiveness. These factors include social norms, policies and laws, marginalisation, criminalisation, stigmatisation and discrimination of key populations, changes and trends in the drug scene affecting the processes related to production, distribution and use of drugs, as well as legislative norms and law enforcement practices that may inadvertently increase the risk of HIV transmission and prevent the delivery of services. A major structural impediment is the penitentiary system, including prisons and pre-trial detention centres. Structural interventions may directly target the negative factors or nurture a supporting environment through so-called critical enablers. These include the empowerment of the affected communities, fostering political commitments and support of advocacy activities, revisions and modernisation of laws, policies and practices, community mobilisation and elimination of stigma and violence.

Structural interventions are an important area of focus for CLM efforts. Examples of structural monitoring include monitoring of regulations and laws impacting harm reduction and HIV services for PWUD. These include not only legislation related to criminal penalties but also regulations related to the use of drug user registries that may be shared with law enforcement agencies and any restrictions on the circulation of harm reduction products such as Naloxone, OST, PrEP or ART. CLM can scrutinise police harassment of PWUD for carrying harm reduction products or medico-police raids requiring forced testing for drugs or HIV and other harmful police practices, as well as monitor the development of evidence-based and public health-aware policing.

[17] Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO.

8. Further Reading / Useful Resources

WHO Guides

- WHO, UNODC, UNAIDS technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users. WHO, 2009. Available at: https://www.unodc.org/documents/hiv-aids/idu_target_setting_guide.pdf.
- Tool to set and monitor targets: supplement to the 2014 consolidated guidelines for HIV prevention, diagnosis, treatment and care for key populations. Geneva: WHO; 2015. Available at: https://www.who.int/publications/i/item/9789241508995
- Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations – 2016 update. Geneva: World Health Organization; 2016. Available at: https://www.who.int/publications/i/item/9789241511124
- Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO. Available at: https://www.who.int/publications/i/item/9789240052390
- Values and preferences of key populations: Consolidated report (Web annex to the WHO guideline: Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. Available at: https://www.who.int/publications/i/item/WHO-HIV-2014.11
- Policy guidelines for collaborative TB and HIV services for injecting and other drug users, 2008. Available at: https://www.who.int/publications/i/item/9789241596930

The Global Fund Technical Briefs

- Harm Reduction for People Who Use Drugs, 2022: https://www.theglobalfund.org/media/1279/core_harmreduction_infonote_en.pdf
- Optimising HIV Prevention Reach for Key Populations, 2023: https://www.theglobalfund.org/media/13033/core_optimizing-hiv-prevention-key-populations_briefingnote_en.pdf

- HIV Programming at Scale for and with Key Populations, 2022: https://www.theglobalfund.org/media/4794/core_keypopulations_technicalbrief_en.pdf
- Prisons and Other Closed Settings: Priorities for Investment and Increased Impact, 2022: https://www.theglobalfund.org/media/12471/core_prisons-other-closed-settings_technicalbrief_en.pdf
- Removing Human Rights Related Barriers to HIV Services, 2022: https://www.theglobalfund.org/media/12445/core_removing-barriers-to-hiv-services_technicalbrief_en.pdf
- Gender Equality, 2023: https://www.theglobalfund.org/media/5728/core_gender_infonote_en.pdf
- Protection from Sexual Exploitation, Abuse and Harassment, 2022: https://www.theglobalfund.org/media/12159/ethics_protection-sexual-exploitation-abuse-harassment-guidance_note_en.pdf
- Community Systems Strengthening, 2022: https://www.theglobalfund.org/media/4790/core_communitysystems_technicalbrief_en.pdf

Other Resources

- FHI 360. Monitoring guide and toolkit for HIV prevention, diagnosis, treatment, and care programs with key populations. Durham (NC): FHI 360, 2020. Available at: https://www.fhi360.org/sites/default/files/media/documents/resource-linkages-monitoring-tools.pdf
- WHO, UNODC, UNAIDS technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users., WHO, 2009, P.9. Available at: https://www.unodc.org/documents/hiv-aids/idu_target_setting_guide.pdf
- Stop TB Partnership. 2015. Key populations brief: people who use drugs. Available at: https://stoptb.org/assets/documents/resources/publications/acsm/kp_peopleusedrugs_spreads.pdf
- UNAIDS. 2021.Global AIDS Strategy 2021-2026. Available at: https://www.unaids.org/sites/default/files/media_asset/global-AIDS-strategy-2021-2026_en.pdf

- The IDUIT – Implementing Comprehensive HIV and HCV Programmes with People Who Inject Drugs. Available at: https://www.unodc.org/documents/hiv-aids/publications/Implementing_Comprehensive_HIV_and_HCV_Programmes_with_People_Who_Inject_Drugs_PRACTICAL_GUIDANCE_FOR_COLLABORATIVE_INTERVENTIONS.pdf
- The IDOIT Brief Guide for People Who Use Drugs, INPUD, 2017. Available at: https://inpud.net/the-iduit-brief-guide-for-people-who-use-drugs/
- Injecting Drug User Implementation Tool (IDOIT) Training Manual. Available at: https://inpud.net/wp-content/uploads/2022/01/000509_INP_IDUIT-Training-manual-1.pdf
- INPUD (International Network of People who Use Drugs) qualitative study on Key Populations' Values and Preferences for HIV, Hepatitis and STI Services. Available at: https://inpud.net/wp-content/uploads/2022/01/INPUD-WHO-Values-Preferences-Study-Report.pdf
- On the A-Gender. Community monitoring tool for gender-responsive harm reduction services for women who use drugs, INPUD. Available at: https://inpud.net/wp-content/uploads/2022/01/INPUD-Gender-Sensitive-Monitoring-Tool-2.pdf

Annex 1: AAAA Framework Guiding Questions

1. Availability

Please note that availability of services does not mean that the services are easily or at all accessed by the communities in need. Issues related to accessibility are listed under area 2 below. Nor does the availability of services mean that they are of acceptable quality or satisfy the needs of the affected communities.

Does the range of services or health products available at the facility/service delivery unit correspond to the evidence-based international guidance, such as the WHO Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations[18]? Does this list reflect the needs of local PWUD communities, peculiarities of the local drug scene, prevalence of harms and high-risk behaviours? Is this facility/service delivery unit stocking the required injecting instruments? Naloxone? Medicines for opioid agonist treatment (also known as opioid substitution therapy, or OST, or opioid agonist maintenance therapy, or OAMT)? Is there sufficient stock to distribute for a month, quarter or year? Disaggregate by specific products most frequently utilised/required by the local PWUD community. Map the PWUD population by specific substances, age, gender, etc. and consider the implications for the required stocks of injecting instruments and paraphernalia for each of the identified segments, taking into account the available estimates of sub-population sizes. Inquire of the service providers and clients (e.g., as part of the client satisfaction survey) regarding the stockouts of prevention commodities and medicines. Inquire into the reasons for the stockouts or failure to stock. This information can inform the advocacy and service development efforts. Stockout rates can be calculated for specific commodities as the number of days that the facility was out of stock during each of the reported stockouts. The rates can be compared between various providers. Note the quantities of commodities offered to each client in a given period of time.

[18] Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO

Are they sufficient to fully satisfy the needs of clients in sterile injecting equipment and other health products? Are the quantities in line with World Health Organisation (WHO) recommendations or their national equivalents?

Are there quotas or exchange rates applied to the number of injecting instruments available to clients? What is the rationale for these quotas? Are needles and syringes provided sufficient to address the known/reported patterns of injection for the drug(s) in question?
Consider the above questions in relation to other essential health products and services important for people who inject drugs, such as self-testing for HIV, testing and treatment for Hepatitis C virus (HCV) or pre-exposure prophylaxis (PrEP) for HIV infection.

2. Accessibility

Are the areas where PWUD are known to reside covered by outreach and service delivery teams? What are the realistic coverage areas of the existing stationary service delivery units (drop-in centres)? Are there mobile outreach teams that bring the services to remote areas of the location? Is there online counselling and service navigation? Is there home delivery of HIV prevention commodities? What shares of the target population are covered by each of these service delivery modalities? Are the services tailored to specific segments of PWUD community? Is the programme tracking the utilisation of services by the key segments within the community, such as men and women, various age groups and users of various types of substances? Clients with various gender identities or sexual orientations? What modifications have been introduced to tailor the available services and products to the needs of these specific communities? Is the programme actively promoting services using the appropriate communication channels and media?

Are the hours of operation aligned with the lifestyles and preferences of the target population? Are these preferences different for different sub-populations? For OST, are services available before or after working hours so that patients receiving medicine can have regular jobs?

Are harm reduction products and services available and accessible in prisons, pre-trial or other detention centres? Most penitentiary institutions have significant numbers of PWUD who also require harm reduction services. Are they able to initiate or continue receiving services and products in detention?

Is the programme able to offer or refer the clients to social and other complementary services required by the target communities? These may also include humanitarian services that people require in times of humanitarian crisis. Poor access to essentials such as food, hygiene products and facilities, poor housing conditions, lack of childcare support, domestic violence and mental health challenges may prevent PWUD from prioritising health and the reduction of drug-related harm. Are referrals to the required complementary services well-organised and functional?

Are there any paid components of the service for the clients? How affordable are these, and how essential are they for the clients? These may include fees for certain diagnostic procedures, medicines or commodities, resources required to travel to the facilities or payments for the delivery of health products. What are the sources of funding for the service, and how sustainable are these sources? Does the programme explore any alternative funding opportunities? Are measures taken to increase the cost-effectiveness of the programme?

3. Acceptability

A simple ranking of services on a scale of 1 to 5 can be applied as the simplest client satisfaction measurement. However, in order to better inform the follow-up remedial action, it is recommended to break client satisfaction ranking into several most significant characteristics of the services and collect specific satisfaction level for each of these characteristics.

Are the services free from stigma and discrimination? Are there ethical and attitudinal standards in place for service providers? Is there a mechanism to report or address stigma and discrimination?

Are the human rights of patients promoted and protected? Do programmes have protections against sharing data with police? Arrangements with local law enforcement not to harass or arrest clients on or near premises?

Is participation in the programme and accessing the services safe and secure for the clients? Are there sufficient measures in place to protect the confidentiality of marginalised clients and safeguard sensitive or identifying information?

4. Quality

Are there sufficient supplies of high-quality medicines, injecting paraphernalia, condoms, lubricants and other commodities to meet the needs of clients?
Are healthcare providers delivering prevention services adequately trained and competent in providing accurate and up-to-date information?
What is the average waiting time for accessing HIV prevention services, and is it considered reasonable by clients?
How easily can clients access referrals to other support services if needed, and do they find the process straightforward?
To what extent are healthcare providers using a client-centred approach in delivering prevention services? Do clients feel that they are offered clearly explained options and that the staff acts on their specific prevention needs?
Are clients engaged in the decision-making process for their prevention plans and strategies?
How do clients rate the overall experience of accessing and using HIV prevention services?

Annex 2: General Approach to Monitoring HIV Interventions

The overall monitoring efforts related to HIV services focus on populations most affected by the epidemic, including people living with HIV (PLHIV), PWUD, men who have sex with men (MSM), sex workers (SW) and prisoners. Monitoring measures are designed to track progress of the activities aimed at preventing new HIV infections in these populations and the onward transmission of the virus. The programmes at national and local levels set specific targets based on the estimated population size that needs to be involved in HIV prevention efforts, study the risk profiles of various key population sub-groups, monitor HIV prevalence rates and the coverage of HIV prevention efforts, develop client registration and service delivery monitoring systems to ensure the adequate coverage, the required regularity of service use and avoidance of duplication. Measures are also taken to ensure the implementation of programmes responds to the actual needs of the clients and that services are delivered in accordance with the set key parameters and quality standards. Finally, the monitoring data are regularly processed, analysed and reported to coordination bodies, governing and management structures in order to assess the progress and introduce improvements to make the programmes sufficiently scaled and effective. Good monitoring programmes do not put communities or service providers at risk and guarantee confidentiality and data security at all levels of the programme. Each of these elements of the standard monitoring system may have deficiencies and may require specific attention of the affected communities as part of community-led monitoring efforts. Below, we provide a more detailed outline of each of these components.

1

Accurate estimates of the key and affected populations residing in a given area are the first details required for developing and monitoring HIV prevention/harm reduction efforts.

Detailed and regularly updated estimates of the size and locations (physical and virtual) of key populations (KPs) allow for realistic targets to be set for outreach and determine the required infrastructure, personnel, and budgets. This is a possible area of focus for CLM efforts, as in some countries, accurate estimates of marginalised communities do not exist or are difficult to obtain. Some countries underestimate the size of marginalised communities to avoid negative perception by the societies/stakeholders in other countries that are not directly involved in public health, etc. In such contexts, the organisations involved in CLM activities may focus on obtaining relatively accurate local estimates that allow for setting realistic local targets without challenging the national-level estimates.

Distorting the actual size of marginalised populations may also have economic implications related to allocating public funding to resolve health and social challenges facing disadvantaged populations. These issues may again be easier and more realistic to address at the local level, where the required budget allocations can be distributed between various sources and more transparently monitored by local community activists. At local levels, stakeholders can compare the relative magnitude of investments in related areas and advocate for decreasing or stopping the funding of less effective interventions.

2 **In addition to estimating the sizes of key populations, it is also important to understand the risk profiles of specific population groups.**

Various communities and groups within KPs may differ significantly in terms of their exposure to HIV, specific behaviours that affect the risk of HIV transmission, the influence of contextual factors such as socio-economic status, the effects of criminalisation of marginalised groups, gender inequalities and harmful gender stereotypes, stigma and discrimination affecting access to essential services and exposure and perceptiveness to communication campaigns. CLM ensures that the risk profiles use locally obtained data rather than assumptions based on international experience, which tends to be general or superficial and may mask specific characteristics essential for developing appropriate local solutions.

3 **The monitoring efforts should also establish HIV prevalence rates in the target population and the coverage of HIV interventions.**

HIV prevention and care efforts are primarily focused on the communities with the highest prevalence of infection. High coverage of the most affected communities is the core task of HIV programmes, especially in concentrated HIV epidemics, i.e., those predominantly contained within the key populations. HIV prevalence data in marginalised communities may be challenging to obtain for public agencies, and in some countries, the efforts to detect HIV in these populations are not sufficient. Effective HIV detection in key populations is only possible with the engagement of the affected communities in the development and implementation of HIV testing services. Communities are also best placed to judge whether the existing testing programmes are using the best possible outreach and service delivery mechanisms and human resources. Poorly organised testing may produce underestimated prevalence rates, which in turn lead to insufficient investment in KP-focused HIV prevention and care programmes.

Other important aspects of programme monitoring include:

4 **Individual tracking of KP members to ensure they regularly access the required services.**

Registration of clients and assignment of unique identification allows to track the delivery of services to specific individuals, track coverage of interventions and scale-up progress, plan the intensity of interventions such as the number of distributed commodities, regularity of testing, as well as changes in health status and behaviours by comparing data collected at different points in time. Tracking individual clients also allows to avoid duplication of services, thus ensuring the efficient use of limited resources. It is common for programmes (especially funded and/or managed by governmental agencies) to collect personal data from clients (such as national ID data) as a requirement to access services.

This, however, carries considerable risks related to the possible disclosure of sensitive information related to health status and socially disapproved or criminalised behaviours such as drug use or non-heterosexual orientation. The use of unique identification codes (UIC), which are not linked to personal data and do not allow the identification of a specific person while ensuring the uniqueness of each service recipient, is the preferred solution to eliminate the risk of disclosure. The use of UIC may be challenging to accept for governmental agencies, for example, due to the regulations requiring reporting the distribution of commodities and delivery of services funded from the state budget. CLM can play a significant role in supplying arguments for the use of UIC for tracking service delivery for marginalised populations.

5

Regular monitoring of programmes to ensure that prevention, testing, treatment, and care services meet the needs of KPs and are run efficiently. This monitoring includes regular analysis of tracking data by those who deliver services, as well as by their supervisors, and use of data in real time to manage programmes and improve performance at scale while maintaining service quality.

The relevance of HIV and harm reduction services to the target communities may not receive sufficient attention in the official monitoring systems. CLM has an essential role to play in this area. Examples include the need to accommodate the specific characteristics of prevention and harm reduction commodities and services that are essential for their users, such as the quality of needles or condoms, length of take-home period for the OST medicines or unrestricted access to naloxone – the only effective medicine to protect opioid users from lethal overdose.

6

Regular reporting of data to subnational and national programme levels as required by the government or other funders.

Decisions regarding what data are reported to programme managers and funders do not always take into account the community perspectives. Verifying the relevance of reported data and identifying essential aspects of programme implementation that need to be additionally featured in the reports and the resulting action can be an important and legitimate function of CLM initiatives.

7 Ensuring data confidentiality and security at all levels of the programme.

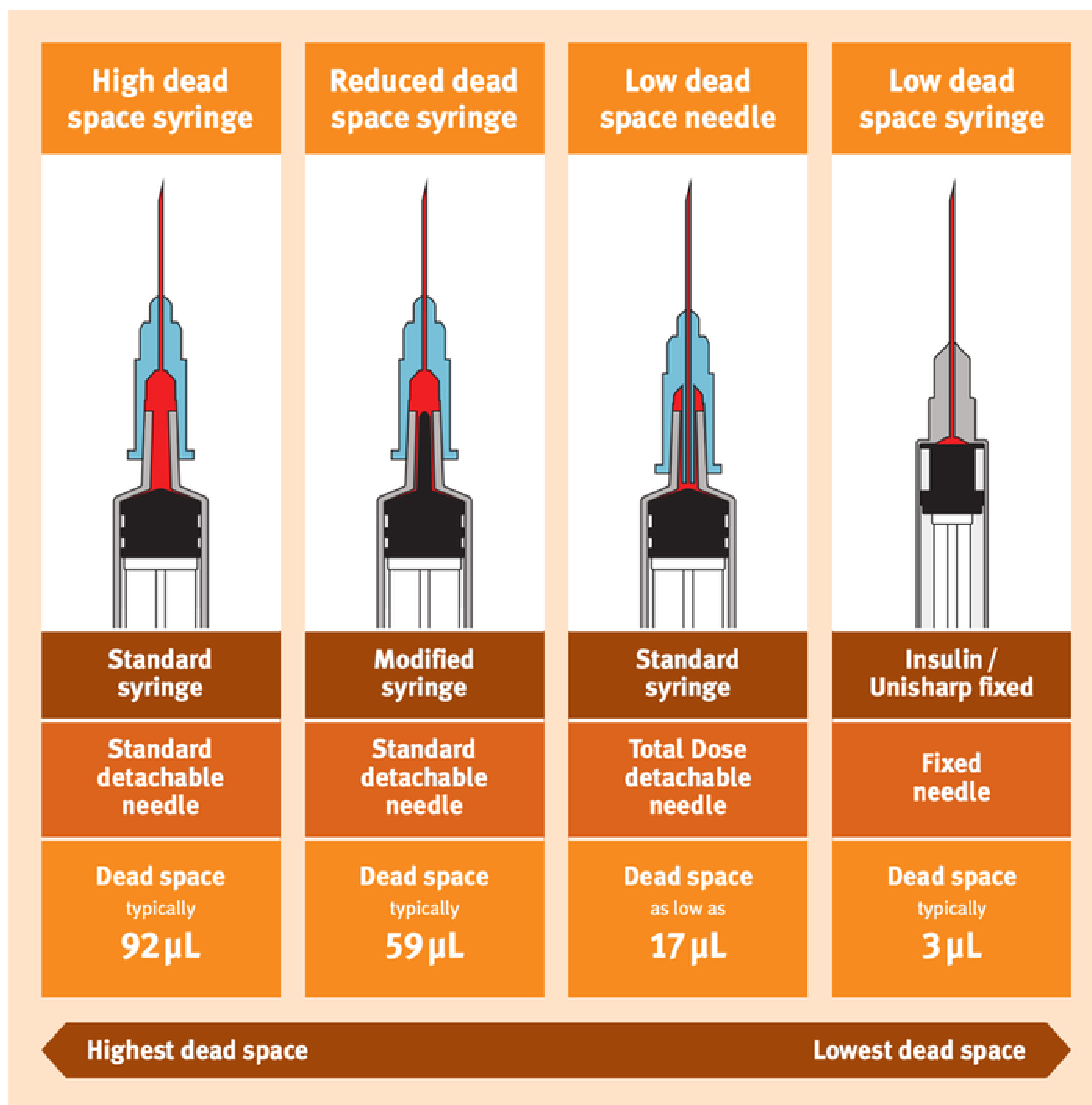
We have already mentioned the use of UIC as an important tool in ensuring data confidentiality and safety of intervention clients. There are other aspects of data security that need to be taken into account and may be monitored by CLM initiatives. These include regulations of access to data containing identifiable personal information as well as policies preventing data leaks and disclosure of sensitive information at the level of service providers.

Annex 3: Low Dead Space Injecting Instruments

The role of the size of the so-called dead space in a syringe has been demonstrated by several studies. The dead space is a space that contains some remaining liquid in a syringe with a fully depressed plunger. The larger dead space carries a larger amount of substance potentially contaminated by blood and carrying a larger number of HIV copies. The reduction of dead space reduces the risk of HIV infection as fewer copies of the virus may enter the bloodstream of the person reusing someone else's syringe. Picture 5 illustrates the relative amount of liquid contained in dead spaces of various combinations of syringes and needles. On the left is a standard syringe with a detachable needle, which has the largest dead space. The next to the right is a modified syringe with the dead space reduced by a special extension of the plunger displacing some liquid from the tip of the syringe. The next one is a standard syringe with a modified needle that also displaces some liquid from the syringe tip. Finally, on the right is a syringe with fixed needle, also called an insulin syringe. The insulin syringe construction allows for the maximum reduction in dead space, which could be as much as 30 times lower than in a standard syringe.

Despite their obvious advantage in terms of the dead space size, fixed needle syringes are only available in small sizes that are not suitable for administering substances in larger volumes. The non-detachable design also has certain shortcomings from the perspective of users in some contexts, which should also be taken into account.

Picture 5. The differences in dead space between various types of syringe and needle combinations[19]



All dead space measurements independently carried out by the Department of Engineering and Microfluidics, Southampton University.

[19] The illustration by Exchange Supplies, UK: Maximising the effectiveness of needle exchange with low dead space syringes and prevention of accidental sharing. Accessed on 30 November 2022 at: https://www.exchangesupplies.org/pdf/F722_LDS.pdf.

Characteristics of a Safe Syringe[20]

- Allows free and full aspiration (up and down motion of the plunger);
- Syringe barrel is clearly visible at the point to determine the presence of air bubbles and blood during injection;
- Plunger must move freely to permit one-handed injection;
- Syringe barrel must be slim enough to allow for the greatest possible positioning of syringe at an angle necessary for injection; and
- Removable plunger to allow for retrieval of contents in the event of a syringe failure.

Beyond these essential elements, it is further possible that a safety syringe may:

- Allow for reversible, manual, voluntary activation of a disabling mechanism to reduce the possibility of third-party syringe reuse or accidental needle stick. Note that this disabling mechanism must be active to the point where any accidental disabling is impossible. This disabling mechanism can involve covering the needle tip, locking plunger or otherwise disabling the syringe.

Characteristics of an unsafe syringe

- A syringe which locks or is passively disabled after a single use or can be accidentally disabled; and
- A "non-reusable" syringe which is rendered non-reusable in any way that:
    - does not permit full aspiration
    - obscures visibility of contents of the syringe barrel
    - makes the plunger move with difficulty
    - means that the syringe barrel is thick to the point at which angle of injection is inhibited would result in the loss of syringe contents in the event of a syringe failure.

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[20] Quoted from: http://www.exchangesupplies.org/article_retractable_and_safety_syringe_debate.php. Accessed on 30 November 2022.

Annex 4: Taking into account the client requirements in the development of technical specifications for procured injecting equipment

Field testing of injecting equipment prior to any bulk procurement is essential. Acceptability of specific parameters, such as the ease of plunger movement, can only be defined through field testing. On the one hand, the easier the plunger moves, the lower the likelihood of needle movement and its exit from the vein during injection. On the other hand, too easy plunger movement reduces the suction and makes it more difficult to draw blood into the syringe in order to ensure that the vein is penetrated. The ease of plunger movement is inversely proportional to the diameter of the cylinder. Only PWID can define the optimal balance in the local context.

Optimal needle thickness also depends on a range of factors, including the type of injection (intravenous or intramuscular) and the place of injection. If a needle is too thin, it gets damaged (dull) much easier than thicker needles during production, storage, transportation and use. A damaged needle causes excessive skin tension and more pain at the time of puncture. An undamaged needle practically slides through the skin and muscles during injection, while with a dull needle, the user feels when the needle penetrates the skin surface and the vein wall. The passage of the needle through the vein wall is similar but even more painful. Even if the user obtains the needles undamaged, thin needles are easily damaged during the preparation of the drug when stirred with the needle tip. When a filter is used, it is common to draw the solution through the needle with its tip touching the filter. This also may lead to dulling of the needle. The needle also gets dull as a result of difficulties with finding a vein, which are experienced by the majority of people with a long history of drug use. Multiple punctures of skin in search for a vein lead to needle tip damage. The thinner the needle, the easier it is to damage.

Different drug preparations require different gauges of needles for injection. Different users prefer injecting in different locations on the body, also calling for different gauges of needles.

Incomplete dissolution or failure to heat solution may lead to clogging of needle with insoluble particles or slow passage through the needle due to excessive thickness of the solution. This makes the use of needles thinner than 27G impractical. Thus, the use of thicker needles often reduces the number of failed attempts to inject and, ultimately, causes less damage to tissues than thinner needles. It is recommended that programmes stock needles of different thicknesses. Clients' preferences vary significantly depending on the length of drug use, mode of preparation and preferred drug type.

Annex 5: Themes and Methods of IEC Work

Themes of IEC work

The thematic range should cover all the issues related to the reduction of risk of transmission or acquisition of HIV and other harms associated with drug use, as well as daily issues of significance to clients. The themes may include:

- Detailed analysis of HIV transmission/acquisition risks and other negative consequences of drug preparation, transportation, distribution and use. While working on this and the following themes, it is recommended to take into account vulnerability factors associated with gender, age and other significant social and demographic characteristics of the clients;
- Objective information on various psychoactive substances, nuanced information on their positive and negative effects, substance-specific harm reduction advice, information on substance interaction and particularly dangerous combinations of substances;
- Detailed analysis of risks associated with unsafe sexual practices, also in relation to the use of substances to modify sexual experiences (chemsex);
- Detailed explanation of available services, programme admission mechanism, addressing common misconceptions regarding the offered services;
- Methods of safer drug use and HIV prevention (safer preparation, transportation, and distribution of the drug, managing the use of injecting equipment, methods of disinfecting of injecting equipment, disposal of waste and handling used injecting instruments), vein care, overdose prevention and management. Promotion of shifting to non-injecting drug use and prevention of transition to injecting;
- Regulatory information and legal advice on issues related to substance use and handling, how to access legal assistance;
- Safe sex methods, including the use of condoms and safer sex negotiation skills;
- Managing drug dependence, available drug treatment and rehabilitation methods, with special focus on opioid agonist treatment;
- Prevention and management of overdoses. Use of Naloxone. Drug checking. Emergency aid including resuscitation techniques (also for relatives, partners and friends of PWUD);

- Transmission, acquisition, prevention, diagnostics and treatment of HIV. HIV influence on health and life with HIV infection;
- Transmission, acquisition, prevention, diagnostics and treatment of other sexually transmitted infections (STI);
- Viral hepatitis: risks, prevention, diagnostics, and treatment. In particular, PWUD should be provided with reliable information on the ways of transmission of hepatitis, prevention methods, and location of testing and counselling facilities. The clients should be aware that hepatitis lives longer than HIV outside of the human body. The importance of hygiene and keeping all instruments including tourniquets and working surfaces clean should be emphasised. The clients should be provided with advice on healthy diet and the need to reduce consumption of alcohol and other aspects of a healthier lifestyle;
- Tuberculosis: risks, prevention, diagnostics and treatment;
- Reproductive and sexual health of PWUD and their sexual partners (protection of motherhood, pre- and post-natal care, safe delivery, measures to prevent sexual transmission of HIV and other STIs, STI diagnostics and treatment, prevention of unwanted pregnancy, family planning, termination of pregnancy, prevention of vertical transmission of HIV. Reproductive health services should take into account possible interaction of medicines such as interaction of hormonal contraception with tuberculosis (TB) medicines, as well as the need for early diagnostics of tuberculosis among pregnant patients with HIV and their new-born babies;
- Information on opportunities to obtain access to other services, including explanation of referral mechanisms, opportunities to access social payments and benefits, and legal and other support that the clients may require.

Effective methods of IEC work

- Group exercises conducted by peers or other specialists, including workshops, demonstration sessions, and role plays (e.g., training on skills in safe sex negotiations, safer injecting techniques, overdose prevention and management, lapse prevention skills, etc.);
- Individual sessions and consultations conducted by peers or other specialists;
- Inclusion of IEC and motivational element in the initial contact of the client with outreach or social worker;

- Development and distribution of printed materials and visuals, including distribution of thematic brochures, leaflets, and periodicals (including those designed by PWUD) through outreach;
- Use of packaging of prevention commodities as a vehicle for communication messages;
- Use of digital IEC means;
- Telephone and online counselling;
- Use of mobile communication and Internet for the distribution of textual and visual information.
- Use of Motivational Interviewing techniques
- Use of screening tools for detection of associated infections such as TB and mental health conditions.

Note: Use of mass media (such as national or local media, local radio, commercial boards, leaflets, advertisements, speeches by celebrities, websites, blogs, and electronic forums) can be effective for working with the general public, e.g., to form positive public perception of harm reduction programmes, rather than with PWUD. Poorly thought-out use of such media may result in further stigmatisation of PWUD and waste of precious resources that could otherwise be spent on more effective interventions.