**Community Led Monitoring of HIV Prevention and Harm Reduction Programmes**

*Tool for CLM Implementers*

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# Introduction

ATAC developed this tool as part of the EANNASO-APCASO-ATAC Consortium within The Global Fund to Fight AIDS, Tuberculosis and Malaria, Community Led Monitoring Strategic Initiative’s C19RM component.

This tool is designed for representatives of communities most affected by HIV in different corners of the world that have an intention to engage in community led monitoring of HIV prevention, care and treatment services.

This tool is not a comprehensive guide but rather a starting point that gives a broad overview and practical hands-on advice to approaching the CLM process for HIV prevention programs.

Most materials focused on CLM implementation deal with monitoring data related to treatment, while prevention, a crucial part of the epidemic response, is often left out. In this tool, we focus on prevention and try to provide the community activists and organisations’ representatives with a resource to guide them through the relevant processes.

## Approach to Monitoring of HIV Prevention Efforts

The overall monitoring efforts related to HIV prevention focus on populations most affected by the epidemic. 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.

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| **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 efforts**. |

Detailed and regularly updated estimates of the size and locations 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 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.

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| 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.

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

**Other important aspects of programme monitoring include:**

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| 4 | Individual tracking of KP members to ensure they regularly access the required services. |
| 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. |
| 6 | Regular reporting of data to subnational and national programme levels as required by the government or other funders. |
| 7 | Ensuring data confidentiality and security at all levels of the program. |

## 

## Community Led Monitoring– Essential Principles and Key Objectives

Community led monitoring of health services is a practice that combines systematic and routine data collection by communities with evidence-based advocacy to improve accountability, governance and quality of HIV and health services.

The Global Fund defines CLM as “Mechanisms that service users or local communities use to gather, analyse and use information on an ongoing basis to improve access to, quality and the impact of services, and to hold service providers and decision makers to account”[[1]](#footnote-1).

According to ITPC[[2]](#footnote-2), a leader in community monitoring of HIV treatment and care, there are five key conditions required for effective community led monitoring, namely:

* 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 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** from 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**.

CLM efforts are collaborative and intended to engage multiple stakeholders to co-create and implement solutions instead of assigning blame.

### 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 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 identifyany 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.as
* Through literature review (local and international) and in-depth consultations with specialists, we build our understanding of how similar interventions are implemented in other contexts to shape our own interventions. This includes:

1. the nature of the interventions/services,
2. the available/optimal/state-of-the-art/potential/promising delivery mechanisms,
3. 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),
4. common challenges and solutions.

* Full assessment of the service we monitor: availability, accessibility, acceptability, affordability and appropriateness. 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.
* 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.
* Finalisation of analysis. Production of findings and recommendations for specific purposes. Implementation of advocacy agenda.
* 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 andrestrictions and confidentiality arrangements.

### CLM outcomes

The ultimate outcomes may be considered as exceeding the mandate of CLM activities per se. However, any CLM will be void if it does not lead to specific service improvements. The results of CLM can inform the improvements and adjustments to the following aspects of service delivery:

* Processes
* Standards, protocols andlicensing
* Algorithms, guides androutes
* Commodities and their specific characteristics (including community-defined parameters feeding into procurement and supply processes), quotes and packages for specific segments of the beneficiary population. Regularity/frequency or access
* Supply chains and access modalities
* Personnel: qualifications, experience, attitudes, efficiency, workloads, training, supervision and support
* Marketing and promotion of the services, introduction of complementary services
* Policy and regulations affecting access to and quality of services
* Other measures that can improve equitable access to services for specific sub-populations
* Costs andfunding reallocations

### Data Collection in CLM

*PLEASE REFER TO SPECIFIC TOOLS RELATED TO DATA COLLECTION AND MANAGEMENT FOR MORE COMPREHENSIVE INFORMATION ON THIS TOPIC*

Quantitative and Qualitative Data: Most discoveries are qualitative in nature – unveiling new or previously unnoticed aspects of things. Before we study incidence and prevalence, we need to discover the phenomenon that can be measured.

Essential methods of data collection and analysis:

* Desk reviews of available literature such as the Global Fund audit reports, assessments conducted by networks and initiative groups of people living with the diseases and other key and vulnerable populations, research institutions and independent civil society organisations
* Analysis of DHIS and other service delivery monitoring systems
* Facility visits and observations
* Surveys of patients, service providers, healthcare officials and community leaders
* In-depth interviews with services providers and patients

Samples of data collection tools:

* Observation checklists
* Obtaining and working with facility records
* Interview guides
* Questionnaires
* Focus group guides

Refinement of data collection tools:

* Socio demographic data and disaggregation of data in data collection tools
* Processing the data, checking for errors, and data cleaning
* Objectivity and researcher bias
* Supervision and quality control procedures
* Ethical considerations: informed consent, confidentiality and data security
* How to increase the legitimacy of monitoring
* How to ensure sufficient rigour and gain trust and respect of the audience
* Institutional Review Boards

Data presentation (including data visualisations and the use of dashboards and other data presentation tools and software)Repackaging data for specific target audiences and tasks

### Example of a well organised CLM programme

***ITPC Treatment Observatories[[3]](#footnote-3)***

*In West and Central Africa, 48% of people living with HIV are aware of their status, 40% are accessing antiretroviral therapy (ART), and 29% are virally suppressed. Progress towards universal treatment access is stymied by a range of diverse challenges, including drug stockouts, weak health systems, human rights barriers, and low quality of care. In February 2017, the International Treatment Preparedness Coalition (ITPC) established a regional community treatment observatory in West Africa to increase accountability for the UNAIDS 90-90-90 targets* — \_*ambitious global goals for the scale-up of testing, treatment and adherence.*

*ITPC trained and supported national networks of people living with HIV to collect facility-level data along the HIV treatment cascade from 103 health centres in 11 West African countries. The majority of facilities in the sample were large public hospitals and mid-level health centres located in capital cities. From July 2017-June 2018, the regional community treatment observatory conducted 279 interviews and 110 focus group discussions with patients and services providers. Following several refinements to the quantitative data collection tool, 538 health facility visits were conducted from January-June 2018.*

*The monitoring findings were analyzed using the ‘Five As’ framework — availability, accessibility, acceptability, affordability and appropriateness.*

***Availability****: ART stockouts were recorded during 23.4% of health facility visits (95% confidence interval [CI] 19.8%-27.0%), lasting an average of 40.5 days (95% CI 34.2-46.7 days). Stockouts were less common for HIV tests kits and viral load laboratory supplies (e.g. reagents).*

***Accessibility****: Long distances to health centres was the foremost cited barrier to HIV testing and ART. Linkage to care at the monitored facilities was high overall (4,692 positive tests; 4,354 ART initiations), but was lower among key and vulnerable populations, and in countries where ‘treat all’ is not yet policy. Among 81,817 people on ART, 16,491 viral load tests were performed in the six months of the study.*

***Acceptability****: A third of patients rated the quality of services a 3 or less out of 5. A quarter of viral load test results were returned within two weeks, with faster turnaround time associated with improved viral suppression (p<0.05).*

***Affordability****: Payment for care was not cited as a major barrier to services.*

***Appropriateness****: 16% of individuals who tested HIV-positive were members of key and vulnerable populations, yet these groups made up just 7% of people on ART. Young men were less likely to access services than young women.*

*These findings highlight key gaps along the treatment cascade. Ongoing monitoring by communities of people living with HIV is critical to hold governments accountable for the 90-90-90 targets.*

### The Five “A”s Conceptual Framework in HIV Prevention Context

The Five “A"s framework developed by ITPC for monitoring treatment of HIV infection can also be applied in the context of HIV prevention. The following are some of the possible areas of exploration:

1. ***Availability****:*

*Is this facility stocking the required injecting instruments? Is there sufficient stock for a month, quarter, year? Disaggregate by specific instruments most frequently utilised/required by the local PWUD community. Map the segments of PWUD population by specific substances 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 the service providers and clients (e.g., as part of the client satisfaction survey) regarding the stockouts of prevention commodities. Inquire into the reasons for the stockouts. 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.*

*Are there quotes or exchange rates applied to the number of injecting instruments available to clients? What is the rationale for these quotes? Are they aligned with the known/reported patterns of injecting drug use?*

1. ***Accessibility****:*

*Are the areas of the location 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 hours of operations aligned with lifestyles and preferences of the target population? Are these preferences different for different sub-populations?*

*Are referrals to the required complementary services well organised and functional?*

1. ***Acceptability****:*

*A simple ranking of services on a scale 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 attitudinal standards in place for service providers? Are stigma and discrimination condemned?*

*Are the human rights of patients promoted and protected?*

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

1. ***Affordability****:*

*Are there any paid components of the service for the clients? How affordable are these and how essential for the clients? 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?*

1. ***Appropriateness****:*

*This dimension relates to universality of access – whether the services are sufficiently tailored to the specific requirements of all significant segments of the targeted key population. Consider accessibility by significant sub-populations within the target audience: by various age and gender groups, users of various types of substances.*

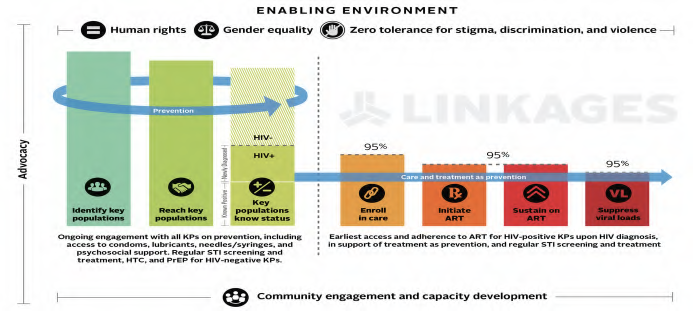
*With regards to services that are not key population specific (not designed specifically for key populations such as needle and syringe programmes and OAT) it is important to compare accessibility by general population and by specific key populations. e.g., it is often the case that the share of known PLHIV in the general population who access ART is significantly larger than that in the key populations.*

**It is essential 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.**

# General principles of HIV Prevention

HIV Prevention is an essential part of 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 the initial contact with vulnerable people and offer friendly and low-threshold HIV testing services.

Comprehensive HIV response is a continuum of prevention, care and treatment services, presented as the following cascade of services (schematised by the US funded Linkages project).



## Essential areas and possible issues

### 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 target the offered combination of services should include not only services designed to achieve the primary HIV prevention and care targets but also a range of complementary services that are designed to generate demand, attract and retain the affected communities in health programmes, as well as to satisfy the essential humanitarian needs of the clients.

These 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 Combination: Balance of Public Health Priorities, Client Needs and Available Funding**

* **Minimum** (usually defined by availability of funding)
* **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 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

### **CLM Focus: Combination of Services**

A possible CLM task is the regular validation of the combination of services offered by prevention programmes. This can be implemented through drawing an inventory of existing services with the analysis of reasons for 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 the optimal service combination and utilise the arguments in advocacy and negotiations of stakeholders aimed to improve the situation.

### Principles of Universal Access

Universal accessibility of services is an important principle that ensures that all underserved communities can access required services. Universal access is based on equity, equality, non-discrimination, and comprehensiveness. Ensuring universality of access requires thorough segmentation of the key populations. Specific groups or segments of the vulnerable and affected populations may have peculiar needs, challenges and obstacles that prevent them from accessing adequate services. For the services to be inclusive, they should accommodate these diverse needs and challenges. For CLM this brings a task of **measuring access and satisfaction with services by all significant sub-groups within the target population**.

WHO recommends a number of parameters for the services to accommodate diverse segments of key populations:

* Physical accessibility of services (geographic spread, access outside of the main cities and for communities residing in remote areas)
* Acceptable cost (cost to clients should not be overburdening and should not prevent people from accessing the service)
* Equity and absence of discriminatory restrictions. Admission procedures should not apply any exclusion criteria apart from objective clinical indications. E.g., opioid agonist treatment should not be available exclusively to PWUD who live with HIV or to those who have unsuccessfully attempted treatment for substance use disorders in the past. Access to ART should not be conditioned on cessation of drug use.
* Absence of quotes for the services. The intensity of the service should be defined by the needs and the demand and should not be limited based on cost or other criteria. E.g., needle and syringe programmes with rigid restrictions on the number of distributed injecting instruments per client are less successful than those that do not set such restrictions.
* Access to services should not be limited based on socio-demographic or other criteria such as:
  + Age. Programmes should not set age restrictions for access to services. In case of children or adolescents who use drugs, special conditions may be required in order to satisfy regulatory requirements such as parental consent for access to health or other services
  + Sex/gender, sexual orientation or sexual behaviours
  + Citizenship, nationality or country of origin, race or ethnic background, status of asylum seeker or religious beliefs
  + Employment status or profession, including sex work, illegal employment, etc
  + Freedom restrictions – imprisonment, military service, treatment in closed healthcare facilities, orphanages, etc
  + Absence or parameters of health insurance
  + History of or current drug use
  + Housing status, e.g., homelessness
  + Mental health conditions
  + Pregnancy

# HIV prevention and reduction of drug related harm among people who use drugs (KEY HIV PREVENTION INTERVENTIONS AMONG PWUD AND WHAT CAN BE THE FOCUS OF CLM EFFORTS)

The following table outlines the complexity of HIV services for people who inject drugs, 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 require the most attention from CLM implementers.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Recommended Service Combination** | | | | |
| **General Principles  and**  **Fundamentals of Effectiveness** | **Recommended Services** | | **Management and Support Functions** | |
|
| **Essential Services** (HIV Prevention and Care) | **Complemen-tary Services** (Attracting and retaining clients, satisfying basic needs) | **Strategic management** | **Provider level** |
| 1. Community engagement 2. Formative assessment and monitoring 3. Outreach strategy 4. Comprehensive case management 5. Service integration and referrals 6. Segmentation of clients 7. Marketing and demand generation | 1. Safer use of injecting instruments (NSP) 2. Generating knowledge, skills and behaviour change (IEC) 3. Reducing injection frequency / Ensuring access to and support of substitution maintenance(OST) 4. Prevention of sexual transmission (Cndm, STI) 5. Ensuring access to and support of ART 6. HIV testing and counselling (HTC) 7. Psychosocial support | 1. Basic health care 2. Hepatitis (Hep) 3. Tuberculosis (TB) 4. Reproductive health 5. Legal support 6. Livelihood development 7. Humanitarian aid | 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 |

## Outreach and Community Involvement

Effective outreach to the most vulnerable is critical even at the stage of population size estimates, as no accurate estimates are possible without established contacts and significant rapport with the affected communities. The establishment of contact and rapport is significantly affected by the long history of stigma and discrimination against the key populations, who often belong to some of the most marginalised communities. For HIV interventions or services to be effective the affected communities must be fully engaged in the outreach efforts, development and delivery of health and other related services.

### **CLM Focus: Outreach Efforts**

**CLM Agenda: Monitoring of Outreach Efforts**

Purpose: To ensure the effectiveness of outreach efforts

What to monitor:

Making sure that the outreach activities are in line with the current knowledge of the local PWUD community.

Consider various types and methods of outreach including e.g., street outreach, mobile outreach, online outreach, chain referral or network outreach (Peer Driven Intervention).

Making sure the client registration and monitoring system allows to accurately reflect the coverage of KP with acceptable level of duplication.

Ensuring safety of the marginalised, stigmatised and [potentially] criminalised clients and their personal data.

Data collection sources and instruments:

Estimates of key population size in the local area.

Ratio of outreach workers to KP.

Client registers with Unique Identification Codes (UIC).

Data safety and security procedures.

### Community Engagement as a Basis for Effective Interventions

Communities are at the centre of healthcare. This is increasingly acknowledged but not necessarily understood. At the surface, this appears to be a matter of courtesy or regulatory obligations of providers towards the recipients of services. In modern healthcare, it is a common practice to explain to the patients the possible healthcare options, the advantages and disadvantages of possible approaches and specific treatment procedures, discuss the treatment plan and regularly check in on the progress during treatment. In this relationship, the patient is informed about the treatment they will undergo and even consulted on certain preferences. They may have a significant say in the doctor’s decisions regarding the optimal treatment course. However, the nature of the relationship assumes the interaction of a specialist or expert with the required qualifications to treat and the patient who is supposed to entrust themself to the doctor’s expertise. The patient is not expected to participate in the professional mechanics of the treatment process as they have not been trained to do so and is not expected to possess the special knowledge required to appropriately organise and manage the treatment. In this relationship, patient’s engagement should ultimately help the doctor or specialist ensure the patient is fully compliant with the treatment process, which is presented as a set of axiomatic rules they are expected to follow to benefit from the service. This approach does not consider several important considerations. First, the universal standard treatment (service delivery) protocol may not be suitable to all categories of possible patients, and the variety of specific individual needs and circumstances that may affect the service delivery relationship is vast. Second, the providers often divert from the expected ideal course of actions, may ignore some of the requirements and disregard some of the aspects that the provider may consider insignificant and the patient may consider essential or vital.

The case of HIV and associated health challenges have demonstrated the complexity of the relationship between healthcare providers and recipients. These complexities turned out to be particularly acute regarding marginalised communities, which were the first to experience the burden of HIV infection. Marginalised communities are particularly vulnerable as their marginalised position makes them more likely to experience stigma or discrimination from providers, makes it more difficult for them to call providers to responsibility, and increases the likelihood of providers’ negligence, particularly in the context of conflicting priorities and excessive workloads. During the long asymptomatic stage of HIV infection, also called chronic HIV infection or clinical latency, which can last for several years (when the untested person may not feel any acute necessity to see the doctor), as well as in the context of prevention, these historically tense relationships with healthcare providers (or any social institutions) simply keep the marginalised people away from health services.

This example demonstrates that without special effort and engagement, it is not possible to ensure access of marginalised communities to services. The efforts should be directed both at the marketing of the necessity to contact the healthcare system (or a mediator such as an NGO-based service), e.g., for regular HIV testing and prevention services, and at improving the quality of health services with a particular focus on nurturing attributes required to effectively serve marginalised communities. Such as inclusivity, avoidance of stigma, understanding of specific aspects affecting the delivery of services such as lifestyles, and co-occurring health conditions, etc. These marketing and quality assurance efforts need to be ongoing, and this is one of the reasons for the implementation of routine community led monitoring efforts in healthcare.

CLM cannot be effectively implemented by people not directly affected by the service. The provider can consciously or unconsciously deprioritise certain essential elements of the service and its delivery due to:

* Overload with work
* Stigmatising attitude towards certain categories of patients/clients
* Lack of clear guidelines for service implementation
* Slow uptake of international standards and good practices
* Interruptions in the supply of required medicines or equipment
* Reluctance to more significantly engage with more complex cases
* Lack of attention to specific circumstances of the patient/client
* Inability to assist the patient/client with addressing social, psychological or other issues that interfere with the service delivery.

Negligence of providers or any other form of suboptimal service delivery is possible because the provision of the service does not directly affect the vital interests of the provider. The personal interest of the recipient of the services gives the necessary rigor to the efforts aimed at organising and ensuring the quality of the service, including the CLM efforts.

### **CLM Focus: Demand Generation**

**CLM Agenda: Marketing/Demand Generation Efforts (Promotion of the Services)**

Purpose: Ensure the services are adequately marketed to generate the demand in the target population.

What to monitor:

Whether marketing efforts are designed by representatives of the targeted communities.

Whether the contents, language, visuals and communication channels are appropriate to the target audience and effectively convey the intended messages.

Whether the intensity and frequency of promotion campaigns is sufficient to achieve the results.

Data collection sources and instruments:

Estimates of key population size in the local area.

Client surveys with regards to the marketing channels and effectiveness of promotional campaigns.

Service delivery statistics.

Documentation of marketing campaigns.

Client satisfaction surveys.

### 

### **CLM Focus: Service Quality**

**CLM Agenda: Monitoring of Service Quality**

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

What to monitor:

Standards of service delivery.

Capacity, qualifications, skills and attitudinal characteristics of service providers.

Level of client satisfaction.

Data collection sources and instruments:

Client satisfaction surveys.

Operational protocols setting standards for service delivery, qualifications, skills and other required characteristics of providers.

Service delivery statistics (compared to the estimates of key population size in the local area).

Structured interviews with service providers.

Documentation of capacity development efforts aimed to improve service quality.

The CLM concept is based on the recognition of the unique role of the communities in ensuring access to and quality of healthcare services. The common justification for this role states that the 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. It is helpful to reflect on these attributes to better understand the mechanisms of effective community involvement.

**Lived experience** relates to direct experience of being a service beneficiary or a failed beneficiary. Recipients of services are particularly sensitive to the characteristics of the service. They are the best places to advise on how the service or delivery mechanism should or should not look. The attractiveness of the service to clients is an essential condition of sufficient coverage and achievement of public health objectives. The threshold of attractiveness is different for various sub-populations of potential service users and even for specific individuals. Vulnerable and marginalised communities have a range of population-specific expectations and requirements for the service to be attractive. Here are some of the characteristics that should be considered by service providers in order to ensure appropriateness of the services:

* Sensitivity to stigma, psychological andemotional vulnerability. Compromised mental health due to a broad variety of additional stressors including, criminalisation, stigma, complex relationships with law enforcement and comorbidities.
* Hectic schedules or schedules that do not fit common daily routines of most people and services.
* 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.
* Cooccurring social or legal challenges related to housing, nutrition, hygiene and childcare.
* Confidentiality (or anonymity) requirements linked to ***criminalisation of personal choices and lifestyles***, disclosure of socially disapproved behaviours, diagnoses to closed ones and social institutions.

Comprehensive CLM of service quality should consider all of these aspects. It is important to address each of them in client satisfaction surveys or other data collection methods so that each significant aspect is measured separately. This will help identify where exactly improvements are required and in designing follow-up technical assistance for providers or other remedial action.

Another aspect to measure is the **employment of peers** by service delivery organisations. Many service delivery functions can only be performed successfully by peers or can be improved significantly with the employment of peers. Examples of functions that can only be performed effectively by peers or people with extensive personal experience of belonging to the community are:

* Outreach
* Delivery of psychological andemotional support
* Service marketing and client education (e.g., treatment literacy from beneficiary perspective)
* Case management
* Community monitoring

In addition to direct employment, **representation of key populations in decision making structures** at various levels is another important CLM area. 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 structures. This strengthens and additionally legitimises the communities in their advocacy to participate in stakeholder coordination and decision-making bodies. Representation processes and the actual performance of representation functions strengthens the associated advocacy power of the communities and allied non-governmental organisations, builds their international connections and allows tapping into the support of international counterparts.

One complex area that can become a CLM focus 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, PWID who are patients of OAT etc.

The difference between basic (which is often tokenistic) and developed levels of representation can be illustrated through the difference between anecdotal and scientific evidence.

**From Tokens to Science: Why CLM takes community engagement to a new level**

**Anecdotal vs Scientific Evidence (Community Engagement vs Community Led Monitoring)**

Anecdotal evidence can be good for discovering the existence of a phenomenon. But it cannot inform about the actual incidence or prevalence of the phenomenon in a given population. This means that anecdotal evidence does not allow judging the significance of the discovered phenomenon. This is why personal experience becomes a valuable asset in public health programming only when there is evidence of significant prevalence of this experience in the population of interest. Involvement of community activists can help highlight aspects of the service that are of significance from community perspective. At the same time, systematic CLM efforts allow for establishing the prevalence of the highlighted phenomenon and deciding whether it should become a focus on ongoing programme improvement efforts. This is important for understanding various data collection and analysis tools (qualitative and quantitative), which is considered in separate tools related to data collection and management.

NOTE ON THE VALIDITY OF OPERATIONAL EVIDENCE. Scientific evidence of effectiveness is a gold standard of validity of an intervention for inclusion in the recommended arsenal of tools that is supported by international donors and governments. However, not many interventions or services are sufficiently studied. E.g., interventions not related to the use of pharmaceutical medicines are often difficult to study due to limited access to funding for research. Also, studies related to the effectiveness of interventions in relatively small specific sub-populations can be scarce, as it is difficult to engage sufficient sub-samples of such groups in clinical trials. Donors and the governments often consider interventions that have not been subjected to experimental research as inferior compared to e.g., well studied ‘hardcore’ medical services. However it is, important to acknowledge the significance of operational evidence of effectiveness collected at the field level by practitioners involved in the implementation of interventions. Although such evidence may not prove the effectiveness of specific operational models in reducing incidence of new HIV infections, it may demonstrate specific successes in achieving concrete operational tasks that lay the ground for further achievement of the ultimate objectives. E.g., this may relate to particularly effective outreach models that bring large numbers of vulnerable people to prevention programmes, HIV testing, care and treatment. Or a particularly successful combination of complementary services that increase retention of clients in prevention programmes. Field level managers may document such promising models and prove their effectiveness with operational studies, which despite the lack of experimental design can support further scaleup of such practices, which may later become subjects of more rigorous studies of their effectiveness.

### CLM Focus: Monitoring the Dynamic Drug Scene and Verifying Relevance of Prevention Efforts

The effectiveness of interventions depends on their relevance in the current context. The drug scenes are constantly changing, and the programme designed a couple of years ago may already become redundant and ineffective and may require significant adjustments to respond to new challenges. E.g., the displacement of opioids by stimulants will lead to very different drug use patterns such as injecting frequency, volume of utilised syringes, and sharing practices. Introducing opioids in opioid-naïve communities will increase the risk of overdoses and require urgent promotion of naloxone, overdose prevention, and management education. The increasing popularity of the Internet and messengers as means of access to psychoactive substances opens new outreach opportunities focusing on online communication and marketing of services.

Assessing the drug scene and contextual factors influencing the vulnerabilities of PWUD is a standard preparatory phase of any intervention. However, programmes sometimes underestimate the need for ongoing monitoring and verification of the relevance of interventions. Communities of PWUD are best positioned to timely identify any significant changes in the drug scene and associated environment and assess whether the current interventions continue to adequately respond to the current conditions.

The following data should be collected in order to systematically monitor the drug scene and related contextual factors:

* Estimated number of PWUD residing in a given location. Disaggregated by specific substances, age and gender
* Patterns of preparation of the substances, transportation, distribution and use
* Patterns of transitions to and from injecting drug use
* Patterns of purchasing psychoactive substances
* Potential locations (including virtual) for effective street, hot-spot and other outreach work
* Behavioural patterns related to substance use and sexual practices that may be associated with increasing risks to PWUD and their sexual partners
* The current needs and challenges as experienced and prioritised by [potential] clients
* Changes in social networking and communication patterns in PWUD community (these are utilised by interventions to reach out and market services, deliver risk reduction communication and education, conduct further studies)
* Patterns of mobility or migration of PWUD
* Changes in the level of satisfaction with services (as this can indirectly signal the dropping relevance of the offered services in the changing situation)
* Any other contextual changes (e.g., in policing and regulatory environment) that may affect vulnerability of PWUD and their sexual partners, their access to and retention in services
* Attitudes of local stakeholders towards the intervention, emergence of new potential allies or opponents

Once changes in the drug scene are identified, it is essential to validate the relevance of the current interventions and develop recommendations for adjustments.

### **CLM Data Collection Tools: Service Quality and Client Satisfaction**

**DATA COLLECTION RECOMMENDATIONS FOR MONITORING SERVICE QUALITY AND CLIENT SATISFACTION**

Client satisfaction data obtained from surveys or interviews with a selection of clients can be triangulated with data from other sources such as the service delivery records, operational procedures of service providers and their internal and external monitoring reports, as well as from direct observations of service delivery. Please refer to the relevant guidance and tools for data collection and analysis.

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 broad variety of additional stressors including criminalisation, stigma, complex relationships with law enforcement, 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, childcare.
* Adequacy of confidentiality (or anonymity) requirements linked to ***criminalisation of personal choices and lifestyles***, protection against disclosure of socially disapproved behaviours or health status information to closed ones and social institutions.

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 PREVENTION EFFORTS?**

Who we are (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 we are at risk)?

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 that knowledge should 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 we should 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 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 it should be? What other properties of a syringe are important? Do we use water for dissolving the substance that we inject?

Do we share syringes/needles/water/filters/cookers/alcohol swabs/stirring tools/syringes or other vessels to mix/prepare the substances before distribution? 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 PrEP? How many of us use PrEP? Contemplate? What else do we need to know to decide on 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)?

Only highly detailed discussion of the practices and risks and the knowledge, skills and means to reduce harm can lead to adequate decisions on the optimal combinations of services offered by providers. Knowledgeable participation of communities in these discussions is enabled by thorough community led monitoring.

### Defining and selecting service providers

Various types of organisations can deliver HIV services to key populations. State run healthcare facilities can deliver broad spectrum of diagnostic and treatment services, including HIV, viral hepatitis, STIs, TB, as well as a range of complementary services such as psychological support and counselling, substance use disorder treatment, etc. However, despite having the capacity to deliver a broad range of services, healthcare facilities normally do not have their own mechanism for finding and attracting patients from marginalised communities. In order to extend their services to key populations, healthcare facilities should collaborate with community-based organisations that have effective outreach mechanisms. Not every non-governmental organisation has an effective outreach mechanism. Most key populations are marginalised and relatively closed communities. To establish contact, it is necessary to penetrate the natural social networks of these communities. This is only possible through members of these networks. Hence, in order to develop an effective outreach function organisations should employ people from the targeted communities. Organisations employing the members of their target community cannot only to organise effective outreach function, but also deliver a range of essential prevention and care services to significant numbers of marginalised clients. However, for medical and other highly specialised services, NGOs have to rely on partnerships with healthcare facilities and agencies that deliver social and other required services. In many contexts, simple referrals are ineffective, and clients require support contacting the reference facilities and follow-up assistance during treatment. This support is most effectively provided by peers with personal experiences of access to the services. Such support can be effectively managed by organisations working in the interests of specific vulnerable communities and prioritising improvements in their quality of life, human rights protection and access to essential services. Focus on satisfying clients’ essential needs as perceived by the clients eventually allows for the generation of demand for health services. E.g., provision of support and contribution to case management by peer workers improves the effectiveness of outpatient treatment thus also decreasing the workload of healthcare facilities and contributing to improved adherence and treatment outcomes. Community-based organisations also play an important role in protecting the rights and interests of their patients and clients, facilitating experience exchange and mutual support between patients and clients, as well as mobilising their families for additional support.

### **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.

Level of client satisfaction with personnel performing various functions related to service delivery.

Data collection sources and instruments:

Client satisfaction surveys.

Operational protocols setting standards for service delivery, qualifications, skills and other required characteristics of providers.

Service delivery statistics (compared to the estimates of key population size in the local area).

Structured interviews with service providers.

Documentation of capacity development efforts aimed to improve service quality.

## Communication in HIV Prevention 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 illicit drugs. 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 simultaneous supply of sterile injecting instruments and other required prevention commodities. Information, education and motivation work, when properly organised and is 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 IEC work is important in the promotion and ensuring the effectiveness of treatment including substitution maintenance and antiretroviral treatment.

Communication with clients is essential for various of aspects of HIV prevention work. This area is particularly challenging to standardise and regulate and can be an important focus of CLM activities. Communication starts with establishing initial contact with the communities, assessing community needs, vulnerabilities and challenges, marketing and promoting the offered services. Immediate contacts with (potential) clients provide a particularly important opportunity and can significantly affect the effectiveness of continued prevention efforts. This is why these communication episodes should be regulated to maximise their benefits. Without clear guidance and communication protocols, the services may miss opportunities for the delivery of important information on risks, risk reduction strategies and skills, service promotion, clarification of needs, referral of clients to complementary services, as well as collecting updated information on the client population and factors affecting vulnerabilities and access to services, such as changes in the drug scene.

The first contact with the service is crucial for building rapport with the client, gaining trust and explaining the benefits of participation. Depending on the success of the first contact, it may also be used to register the client for further participation in the programme, clarification of client expectations and motivation, initial assessment of risks and needs, basic prevention counselling, addressing common myths or misconceptions, testing for HIV, HCV or STI, distribution of prevention commodities. The initial period of enrolment also includes explaining the purpose of the programme and offered services, programme enrolment criteria and process, client rights and obligations, rules and internal procedures of the programme; obtaining client consent for participation, registration of qualifying clients, initial assessment and filing of initial enrolment records, initiation of a case and assignment of a responsible case manager). Even a simple communication protocol is best implemented in accordance with a plan, setting the required issues that need to be covered in prevention communication, skills to be taught, and motivational sessions. Specific communication and guidance accompany the distribution of prevention commodities, tests and other health products.

### **CLM Focus: Prevention Communication**

**CLM Agenda: Communication Work with Clients of Prevention Services**

Purpose: Ensure effectiveness of IEC work as part of the offered service combination.

What to monitor:

Whether the contents of IEC work and specific characteristics of information delivery and skills building supports the achievement of behaviour change targets.

Whether the actual delivery of IEC work is conducted according to the established procedures and standards.

Level of client satisfaction with the contents of communication, the delivery methods and personnel performing IEC functions.

Data collection sources and instruments:

Client satisfaction surveys.

Operational protocols setting standards for IEC work, qualifications, skills and other required characteristics of providers.

Service delivery statistics (compared to the estimates of key population size in the local area).

Structured interviews with service providers.

Structured observation of service delivery.

Documentation of capacity development efforts aimed to improve service quality.

The following are some of the specific requirements for well organised prevention communication, that can become a focus of CLM efforts.

* Involvement of PWUD community in the development and implementation of IEC activities. Communication by peers is more effective in achieving necessary change in behaviour;
* Utilisation of natural social networks of PWUD, their relatives and close environment, as well as sexual partners. It is important to define which communication channels are most utilised in the natural social networks, and attempt to utilise the same channels for IEC purposes;
* Special tailoring for each segment of the target audience;
* Utilisation of the most suitable media channels;
* Combination of various methods of IEC work, including educational peer groups, individual communication, distribution of information through printed materials, Internet, and mobile communication;
* It is not appropriate to reduce IEC work to distribution of printed materials;
* Combining provision of information with practicing practical skills during training and demonstration sessions, utilisation of role plays. IEC in HIV prevention and care is not limited to distribution of information but also aims to change clients’ behaviour through interactive development of skills, formation of intentions, challenging misconceptions and changing social norms in the communities of PWUD;
* Utilisation of group work can be more effective than individual communication;
* Communication should utilise simple and understandable language with the use of visual materials, role plays and demonstrations as appropriate (particularly when working with less literate or less concentrated clients);
* IEC work should not be limited to HIV prevention and other public health challenges, but also provide the clients with information and equip them with skills they require to address their own priority needs and common challenges and risks, which may not be directly associated with health or even drug use;
* Themes featured in communication work should be systematically rotated in order to maintain clients’ interest in provided information. Important themes such as specific risks associated with preparation, transportation and distribution of the drug, benefits of using Low Dead Space syringes, risks associated with the use of water, and risks related to purchasing liquid ready-to-use drugs, should be elaborated in great detail;
* Positive non-judgemental attitude is important as is inclusivity, stigma-free relationship, non-discrimination and acknowledgement of various lifestyles and personal choices with regards to substance use, sexuality and other matters.

### 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 of 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 sexual contacts including sexualised drug use (chemsex);
* Detailed explanation of available services, programme admission mechanism, addressing common misconceptions regarding the offered services;
* Methods of safer drug use and HIV prevention including methods of 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 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. Emergency aid including resuscitation techniques (also for relatives, partners, 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, location of testing and counselling facilities. The clients should be aware that hepatitis live 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 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 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, 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 electronic IEC means;
* Telephone and online counselling;
* Use of mobile communication and Internet for distribution of textual and visual information.

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.

### **CLM Data Collection Tools: Prevention Communication**

SAMPLE COMMUNICATION PLAN FOR PREVENTION WORK WITH PWUD

* Psychoactive substances: their typology, effects, potential harms and risks associated with the use psychoactive substances. Opioids (opiates and synthetic opioids), amphetamine type stimulants, synthetic cathinones, synthetic cannabinoids. Drug interactions. Harms and risks associated with specific modes of administration (injecting, ingesting, intranasal, smoking). Overdose and available antidotes and overdose prevention and management methods.
* 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 of incentives for participation in client satisfaction surveys and other data collection activities.

Use of Motivational Interviewing Techniques

Use of screening tools for detection of associated infections (TB) and mental health conditions

### **CLM Data Collection Tools: Checklist of Prevention Commodities**

**List of essential harm reduction commodities that should be made available by HIV prevention programmes**

* Syringes
* Needles
* Sterile water
* Filters
* Tourniquets
* Naloxone (effective antidote against opioid overdoses)
* Fentanyl strips (rapid tests for detection of fentanyls in samples of psychoactive substances prior to their use)
* Condoms and lube (depending on 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 function
* Accessibility of HCV diagnostics and treatment
* Accessibility of TB diagnostics and treatment

## Needle and Syringe Programmes

Needle and syringe programmes 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 responding to a number of challenges facing PWUD through complementary services. The purpose of needle and syringe programmes 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 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. The likelihood of HIV transmission can be further reduced by ensuring sufficient awareness of PWID regarding the risks associated with preparation, transportation, distribution and use of injecting drugs as well as regarding the effective measures to prevent such risks, as well as by ensuring compliance with the standards of quality and management of programmes managing circulation of injecting instruments. E.g., shifting of PWID to using syringes with low dead space (LDS) can significantly reduce the risk of HIV transmission. Saturation of the market with sterile equipment leads to reduced likelihood of its reuse and sharing. One of the effective strategies is ensuring access to sterile instruments in places where the drugs are prepared and distributed.

Removing used equipment from circulation makes its reuse impossible and increases the likelihood of using sterile instruments. In addition to this, measures aimed at removal and disposal of injecting equipment prevents possible physical or visual contact of the general public with used needles including the prevention of needle stick injuries, which is appreciated by the local community and authorities and facilitates public acceptance of needle and syringe programmes.

### **CLM Focus: Needle and Syringe Programmes**

**Specific Requirements that can be a focus of CLM efforts:**

* There should be NO restrictions of the quantity of distributed injecting instruments to satisfy the needs of clients;
* Injecting instruments with Low Dead Space should be utilised wherever possible;
* Distributed injecting instruments should satisfy key demands of the target audience. These demands are based on the specifics of injecting practices prevalent in a given locality. The needs of the target population and peculiarities of local injecting practice should be taken into account in the development of technical specifications for procurement of injecting instruments;
* The last two requirements may contradict each other in some contexts, and the task of the programme is to ensure the optimal balance, satisfy HIV prevention and other public health requirements, and meet the requirements of clients regarding characteristics of injecting equipment. Distribution of low quality instruments, which do not meet the requirement of clients and do not take into account peculiarities of local drug scene and injecting practices, leads to decreasing demand for harm reduction services and decreasing coverage of the target population.
* The clients should be informed about the safety precautions during handling utilised injecting equipment.

### The essential parameters of needle and syringe programmes

* In depth understanding and regular monitoring of the drug scene and injecting practices including seasonal ones;
* Effective outreach and programme coverage strategy, retention of the close contact and rapport with the target population;
* Segmentation of the target population and tailored outreach and service delivery strategies;
* The types and quality of injecting instruments and other commodities correspond to the local practice of production, acquisition, transportation, distribution and use of psychoactive substances;
* Close integration with the efforts aimed to increase awareness and build the safer behaviour skills;
* Development of mutually acceptable mechanisms of interaction with law enforcement agencies, other relevant authorities and local governments, clinical facilities and other influential structures and associations;
* Pragmatic approach towards prevention of and response to leakage of injecting instruments and other risks;
* Effective mechanisms of staff management and support, particularly staff and volunteers with history of psychoactive substance use.

### ‘One-to-one’ exchange and other exchange rates

Rigid requirements regarding the exchange of syringes and needles, as opposed to their distribution, just as the introduction of exchange rates (giving out a certain number of sterile instruments in exchange of a certain number of used instruments withdrawn from circulation) may significantly reduce the programme effectiveness. The more significant the share of injections conducted with sterile instruments, the lower the likelihood of transmission of HIV and other infections. That is why the programmes are recommended to remove any obstacles to distribution of injecting instruments in the required amounts, including the exchange rates.

In some contexts, possession of injecting equipment may be dangerous to PWID due to law enforcement practices, e.g., when possession of injecting instruments is used as indirect proof of illicit substance use. In such circumstances, the distribution of syringes is more preferable than exchange. The disposal of used equipment can be implemented in other ways, such as through installation of special containers for the collection of used syringes close to the places where drugs are used, collection/exchange of used equipment in shooting galleries and other places where drugs are used, as well as regular events organized to clean the territory off the used instruments in places where drugs are used.

In this issue, the personnel and management of the programmes are recommended to exercise necessary discretion. While encouraging clients to hand in used instruments, the programmes should not restrict the amount of distributed equipment. Wherever possession of injecting instruments does not expose the clients to additional risks, the exchange rates can be utilised to encourage the clients to hand in as many used syringes as possible. The programmes are recommended to use other possible means of encouragement while ensuring the adequate training of clients on handling potentially contaminated equipment.

### Taking into account the client requirements in the development of technical specifications for procured injecting equipment

Testing of injecting instruments prior to any bulk procurement is very 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.

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 is identified by the excessive skin tension 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. When a dull needle is used, the skin is not punctured until tangible effort is applied. When the needle finally pierces the skin this happens suddenly and jerkily, accompanied by a painful sensation. 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 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 long history of drug use. Multiple punctures of skin in search for a vein leads to the needle tip damage. The thinner the needle, the easier it is to damage.

Vein blood is thicker than arterial blood, and it gets even thicker as a result of stimulant use. This makes it more difficult to draw back blood to ensure the vein is punctured.

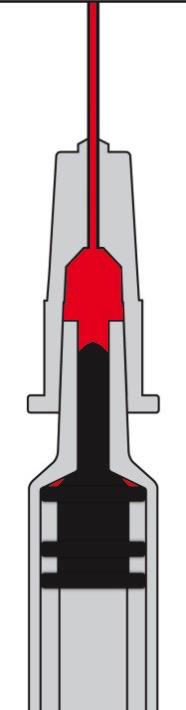
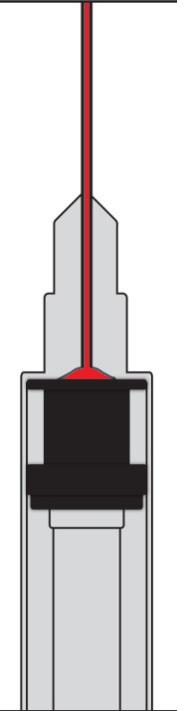
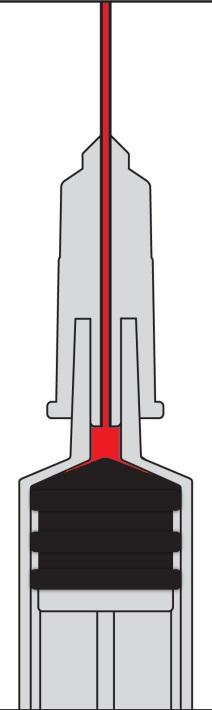
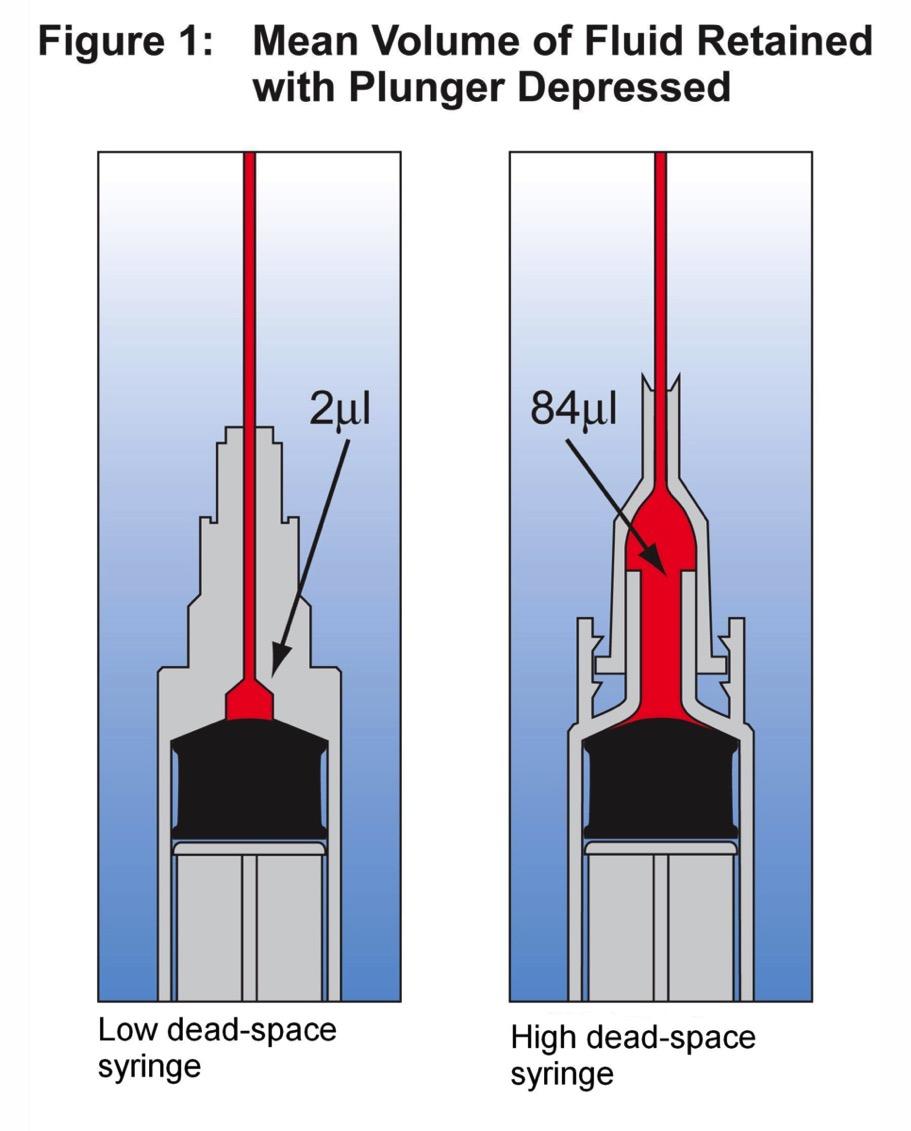
Use of pharmaceutical drugs may lead to clogging of needle with insoluble particles or slow passage through the needle due to excessive thickness of the solution. This makes the use of needles thinner than 27G impractical. Thus, the use of thicker needles often reduces the number of failed attempts to 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 prefered drug type.

### **CLM Focus: Technical Specifications of Injecting Equipment**

Technical Specifications of Injecting Equipment

* Field testing important
* Optimal ease of plunger movement: stability in the vein (no jerky action), suction control (retain suction to define vein penetration), single handed injection
* Optimal barrel diameter (sufficiently thin for optimal injection angle)
* Removable plunger (access to contents if needle is clogged)
* Barrel transparency (visibility of blood and air bubbles)
* Optimal thickness of the needle (injection type and spot, blood thickness and stimulant use, substance thickness and additives)
* Optimal length of the needle (injection type and spot)
* Needle sharpness and resistance to deformations (steel quality): vein searching, preparation and filtration procedures
* NOT self-destructing (non-reusable, auto-disable) syringes: uncertainty and extra risks for the users: sudden lock and loss of contents, length of time and increased exposure to the risk of being caught

Low Dead Space Injecting Instruments

**Characteristics of a Safe Syringe** (quoted from <http://www.exchangesupplies.org/article_retractable_and_safety_syringe_debate.php>)

* 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 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 of the needle tip or 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.

Needle and Syringe Programmes (NSP) are complex interventions, usually containing a broad range of services, parameters and principles. NSPs can include the provision of basic medical assistance such as managing wounds, serving as a centre for referring clients to other organisations to receive treatment for drug dependence, HIV care, support and treatment, as well as other medical and social services. Distribution of injecting equipment should be accompanied by information work, particularly offering clarification 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. WHO 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.

Where it is impossible to distribute injecting equipment, it is essential to inform the users of the risks associated with sharing and specific methods to minimise the risks if sharing is inevitable such as using sterilisation supplies.

## Opioid Agonist Treatment

Opioid agonist treatment (OAT), also known as substitution maintenance therapy, is considered a vital intervention for its direct benefits and access to a range of other HIV prevention and harm reduction services.

Access to OAT promotes transition to **non-injecting modes of administering drugs/reduction in injecting incidence**. Along with supporting motivation for choosing non-injecting modes of administration, OAT reduces the number of injections, including the number of unsafe injections, thus directly influencing the likelihood of HIV transmission. In addition, OAT has been shown to stabilise psycho-emotional state of PWUD, facilitating safer behaviours, reducing risk of incarceration, and improving access and adherence to treatment of HIV infection.

It should be noted here that low effectiveness of other methods of treating drug dependence (apart from OAT) does not allow considering them as significant HIV prevention methods among PWID. However, access to other modalities of substance use disorder treatment responds to essential demands of PWUD and increases the attractiveness of HIV prevention programmes. Compulsory treatment of substance use disorders is not an effective strategy and is not recommended.

### **CLM Focus: Opioid Agonist Treatment**

**CLM Agenda: Opioid Agonist Treatment**

Purpose: Ensure sufficient access to and effectiveness of OAT

What to monitor:

Whether the local standards of OAT are conducive to sufficient access and effective treatment.

Whether the actual services are compliant with the established procedures and standards.

Whether contents of IEC work and specific characteristics of information delivery and skills building supports the achievement of behaviour change targets.

Whether the service providers possess the required qualifications, knowledge, skills and attitudinal characteristics.

Whether the patients have access to complementary services they require to be able to adhere to OAT.

Level of OAT client satisfaction.

Data collection sources and instruments:

Client satisfaction surveys.

Operational protocols setting standards for OAT work, qualifications, skills and other required characteristics of providers.

Service delivery statistics (compared to the estimates of key population size – people who use illicit opioids - in the local area).

Structured interviews with service providers.

Structured observation of service delivery.

Documentation of capacity development efforts aimed to improve service quality.

**Other issues that can be subject to CLM monitoring of OAT**

* Threshold: identifying unnecessary requirements or practices that increase the service accessibility threshold.
* The utilised medicines and their pharmaceutical form. Evidence and contextual considerations.
* Appropriate therapeutic dose based on clinical indications and client satisfaction rather than on rigid facility regulations.
* Take-home doses: making sure practical compromise is in place between the client and provider perception of the optimal take home period and monitoring procedures.
* Testing for illicit substances and the following disciplinary measures. Making sure the patients are not excluded from the service and the coexisting illicit substance use is addressed through counselling and OAT dose adjustments.

Many of the challenges with OAT relate to imperfections of the national regulation and may need to be challenged through national coordination bodies. This requires concerted advocacy efforts of multiple stakeholders, including patient groups and practitioners. However, certain improvements are possible at 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.

### Other types of treatment of Substance Use Disorders (SUD)

Apart from opioid agonist treatment (OAT/OST) other forms of treatment can be utilised 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.

OST is the only type of SUD treatment classified as an HIV prevention and care intervention. The others, despite their relatively low effectiveness, can be considered important services aimed at improving the quality of life of PWID. Organisations aimed at satisfying the needs and protecting the rights of PWID 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.

It should be specially noted that compulsory drug dependence treatment methods, based on detention and forced fulfilment of staff requirements by the detained patients, are unacceptable. In March 2012 International Labour Organisation, Office of the High Commissioner for Human Rights, United Nations Development Programme, United Nations Educational, Scientific and Cultural Organisation, United Nations Population Fund, United Nation High Commissioner for Refugees, United Nations Children’s Fund, United Nations Office on Drugs and Crime, United Nations Entity for Gender Equality and the Empowerment of Women, World Food Programme, World Health Organisation; and Joint United Nations Programme on HIV/AIDS issued a joint statement urging countries to utilise these forms of treatment for drug dependent people to immediately close such institutions and release detained people, as well as ensure that people who require health services can access those in the community settings voluntarily. The statement notes serious breaches of human rights in such centres, low effectiveness of such methods of drug treatment, excessive costs, and their negative influence on efforts to ensure universal access to HIV prevention, care, support and treatment. The international organisations that issued the statement offered necessary support to countries willing to replace such institutions with alternatives, which are more effective from a public health perspective and more acceptable from a human rights perspective.

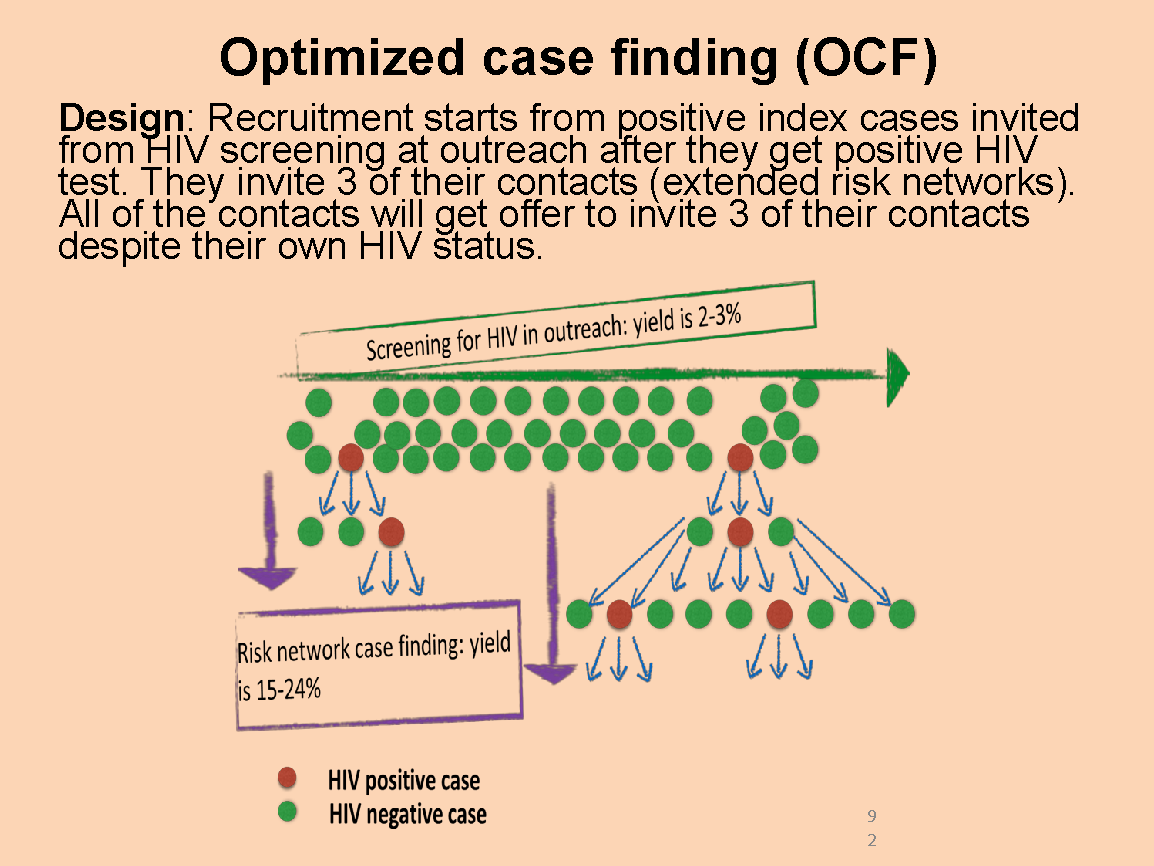
CLM can play an important role in the documentation of human rights abuses and other issues facing patients of rehabilitation and treatment centres, raising these issues with the owners and managers as well as with governmental agencies regulating the delivery of services to PWUD, and advocating for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

## HIV Testing, PrEP and Treatment of HIV Infection

In addition to their direct prevention effect, HIV prevention and harm reduction programmes 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.

The emergence of rapid tests, which can be utilised in the field by non-governmental service providers or even self-administered by KPs, greatly facilitated access to HIV testing and treatment for marginalised communities. 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.Case-finding can be further improved with chain referral outreach and service delivery models such as **optimized case finding (OCF)**. The model uses natural social networks of key populations to offer services to contacts of initial clients who have similar risk profiles and may benefit from HIV testing or other services. OCF is schematically presented below, showing how each of the initial HIV positive cases assists in the detection of other cases in their social environment.



Defining the HIV status of a person sets the key parameters of the client’s case management. It is the fundamental factor in determining the combination of services that will be offered to the client. 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. ART can be more effective for users of opiates if combined with OAT. It is important to note that the existing systems of patient registration contain the risk of confidentiality breaches and disclosure of drug use history, which negatively influences the coverage of treatment programmes, and treatment retention and adherence. It is crucial to ensure that the patients’ information regarding history and current substance abuse status is not passed to law enforcement or used to feed stigmatising attitudes by healthcare providers. It is also important to ensure access to women who use drugs, sexual partners of PWUD to PMTCT services, and support to manage substance use during pregnancy, including access to OAT for opioid users.

Apart from defining the need for care and treatment for PLHIV, the HIV status of the client sets the direction of HIV prevention work (prevention of onward HIV transmission, including ART as one of the prevention strategies, or prevention of HIV acquisition by the client including PrEP). HIV testing is always accompanied by informational, educational and motivational components, which should be delivered follwoing clear protocols or standards. This allows for delivery of essential HIV prevention as well as care and treatment interventions. HIV testing should happen at early stages of workwith the client, ideally during the client’s first contact with programme workers. This is only possible when NGOs conducting intensive outreach work are substantially engaged in developing and delivering HIV testing and related counselling services.

**Treatment of HIV infection** as a strategy to preserve life and a prevention method. In most cases, NGOs are not in a position to directly provide ART and other services containing considerable clinical components. In such situations, NGOs manage effective referral and case management mechanisms designed to ensure timely progression of the clients to ART and their retention in treatment programmes. Taking into account that clinical facilities do not possess their own effective mechanisms for detecting new patients, and usually play a passive role, and that the clinical facilities are characterized by a number of other limitations, which reduce the effectiveness of treatment in marginalised patients, such as PWID, the role of NGOs in timely detection of those in need of clinical care and in ensuring treatment effectiveness (including through the provision of psychosocial support required for treatment retention) is critically important.

Ensuring timely access to ART leads to reduced mortality and increased quality of life of the patients. The treatment effectiveness is significantly higher when people needing treatment are detected quickly and enrolled in treatment early. This is achieved through active participation of HIV prevention programmes implemented by non-governmental organisations, in testing and following integrated case management of HIV positive clients in close collaboration with specialised clinical facilities.

Prevention of *mother to child transmission of HIV* with the use of antiretroviral medication critically reduces the risk of HIV transmission to the baby. All women who use drugs and require PMTCT, as well as all female sexual partners of men who inject drugs should have unrestricted access to this service.

Apart from lowering mortality and improving the quality of life of people living with HIV, ART has a proven *prevention effect*. While acknowledging the significance of utilising antiretroviral drugs in prevention, it should be noted that practical implementation of this work poses a range of challenges, including those related to scaling ART as a prevention measure among PWID in the context of insufficient access to ART in the general population.

The large-scale introduction of this intervention is restricted by a range of factors, including the limited capacity of health care systems in the developing countries, lack of contact and rapport between the health care facilities and PWID communities, insufficient acknowledgement of the role of non-governmental sector in ensuring access to HIV treatment, as well as by a number of factors related to ensuring adherence to treatment and defining the timing of treatment initiation. It should also be noted that even if the methods of using ART as a prevention means are sufficiently developed, this will not diminish the significance of other prevention strategies.

The combined use of different prevention methods is more effective than restricting the response to only one of the possible strategies.

Organisation of HIV testing and follow-up enrolment of clients on ART or PrEP is an important area of community monitoring. 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. Please consult those resources if you are planning to monitor treatment of HIV infection in your community.

### PrEP

PrEP is gaining popularity as an effective HIV prevention measure. Its broader introduction will require significant promotion and patient literacy work, as many people in key populations consider PrEP unacceptable, unnecessary or unfeasible. Concerns relate to feasibility, barriers to ART for PLHIV in the eligible population, stigma around PWID from using services and the far more urgent challenges facing PWID: poverty, homelessness, hunger, illness and criminalization. PWID may understand PrEP as a way to put the responsibility on drug users (with all of the implications they have to face in terms of toxicity, side effects, and daily medicines) rather than a collective, societal effort to promote harm reduction. There are significant concerns regarding potential human rights threats and risks that may be associated with large scale introduction of PrEP in countries where drug use is criminalised. Specific risks associated with the scale-up of PrtEP relate to disclosure of patient data (including substance use) to law enforcement, introduction of regulations requiring compulsory attendance of healthcare facilities and other human rights infringements. Clients are also concerned about the side effects, potential toxicity, costs associated with PrEP, and the general lack of information regarding positive and negative aspects of this prevention method in order to decide whether the public health benefit of PrEP is complemented by sufficient benefits to the individual taking it.

In contexts where PWID are reluctant to access health services, it may not be possible to promote and rollout PrEP without the involvement of community-based and non-governmental organisations. Other challenges may restrict access to PrEP and can be effectively monitored by the communities such as general barriers to ART and significant shortfalls in ART coverage of eligible populations, adherence challenges for people with chaotic lifestyle, risk of additional stigmatisation that would increase the burden of already highly stigmatised and marginalised communities, as well as limited satisfaction to more basic humanitarian needs such as shelter, food, and basic health care. Generally, in contexts where marginalised communities have more general humanitarian challenges such as shelter, food and access to healthcare access to PrEP or any other services that do not present immediately observed benefit is likely to be deprioritised. In such contexts addressing the general humanitarian needs is a necessary prerequisite to ensuring access to and demand for PrEP and other healthcare services.

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 can’t 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.

## 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. Influencing patterns of sexual behaviour may be more difficult than changing injecting practices. Therefore, the effectiveness of preventing sexual transmission of HIV by improving access to prevention commodities and forming the necessary knowledge and skills is likely lower than the effectiveness of measures addressing HIV transmission through injecting drugs.

Distribution of condoms and relevant IEC work should be combined with utilising the prevention opportunities of ART, 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 essential in HIV prevention programmes, as acute sexually transmitted infections increase the likelihood of HIV transmission and acquisition during sexual contact. Thereby timely detection and effective treatment of STIs decreases the likelihood of HIV transmission during sexual contact.

Different segments of key populations may have varying sexual and reproductive health needs. Verification of such needs can be a valid focus of CLM efforts. E.g., prevention of sexual transmission is most relevant for PWUD who are involved in sex work, men who use drugs and have sex with men, men who use drugs to enhance or modify their sexual experiences, and users of stimulant drugs, including synthetic cathinones. Distribution of condoms, lubricants or STI tests with the same intensity across all key populations may be a waste of resources. CLM can contribute to the verification of SRH and other needs of various segments within key populations and produce recommendations for adjusting the offered combinations of services and commodities.

## PWID vs PWUD – is it worth it to target non-injecting users with HIV prevention services?



The initial focus of HIV prevention efforts, and a big boost to the development of harmreduction services, was related to the HIV epidemic in the communities of people who inject drugs. Injecting drug users was defined as a key population most at risk and 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 on people most at risk of acquiring (KPs) or transmitting the infection (PLHIV) is most effective in the initial phases of HIV responses, as it addresses the immediate risk of HIV transmission among the most affected. When HIV prevention and detection efforts reach a certain threshold, it becomes increasingly difficult to engage the remaining segments of KPs. It is also important to address rotation of the KPs, which supplies new members to the main target populations of the HIV response. Newly initiated KPs are most likely to come from the proxy KPs – populations of people sharing certain behavioural patterns with KPs and experimenting with high-risk behaviours without necessarily self-identifying with any of the KPs. A large proportion of these proxy KPs are young people experimenting with psychoactive substances and exploring their sexuality.

Many specialists speak for expanding harm reduction work to include recreational users of psychoactive substances. Most of those prefer non-injecting modes of administering drugs, such as smoking, snorting or swallowing.

There are several significant reasons to engage non-injecting users in harm reduction and HIV prevention programmes. These are the following:

1. **Experimenting, recreational and** **non-injecting users of psychoactive substances are important populations that play a significant role in the epidemiological process**. Although HIV infection primarily concentrates among KPs (including people who inject drugs, it should also be noted that the opportunities to detect HIV in classic key populations are currently being exhausted. This brings the task to explore the less familiar segments of key populations and bridging populations, including **people in transition to entering KPs** and **sexual partners of KPs**. Transitional or proxy KPs, is a more precise term for young key populations. Many of the younger people who practice high risk behaviours lack KP self-identity and do not face the same degree of risks and challenges as their older counterparts. Young people in modern society may practice high risk behaviours without reflecting or associating themselves with more complex sexual identities beyond the heteronormative framework. 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 have not yet formed the KP identity and are not attracted by social marketing and services targeting KPs.
2. Most existing programmes targeting key populations serve mature adults and do not, attract younger segments of KPs. Young KPs are underrepresented in IBBS samples and there is limited information available on the role of younger groups in epidemic dynamics. Most people recourse to prevention and care facilities when they face significant problems associated with high risk behaviours such as HIV infection, viral hepatitis, chronic STIs, medium to severe substance use disorders, other mental health problems, violence, legal problems, and severe disruptions in their socio-economic condition. Ensuring access to objective and reliable information on high risk behaviours, their positive and negative implications, and effective measures to reduce associated harm, as well as engaging younger segments of KPs in effective harm reduction and HIV prevention interventions **early** allows to prevent HIV infection and the onset of other significant harms associated with high risk behaviours, establish contact and rapport with KPs earlier in their careers, and prevent transitions to riskier practices such as injecting drug use.
3. Interventions for experimenting young people are among a few available tools to engage younger segments of key populations in HIV prevention and harm reduction activities. These interventions include harm reduction services for experimenting and recreational users of psychoactive substances and online outreach, screening, counselling, and navigation to services for younger segments of KPs, proxy KPs and bridges (sexual partners).
4. A sizeable proportion of non-injecting users develop problematic patterns of use (such as experimentation with and **transition to injecting use**), **substance use disorders** and other **mental health conditions**, which present a growing challenge for society and the public health system. According to IBBS data in Ukraine, the annual rotation of PWID population is 7%, which means that as many as 20,000 people may be transitioning from non-injecting to injecting substance use each year. Thus, engaging non-injecting users in prevention interventions is an important means of restraining the initiation to injecting drug use and overcoming the HIV epidemic. Transitioning to injecting is a process that includes **formation of identity** as a person who injects drugs. Long before this self-identification is complete, a person may occasionally inject without realising the need to access services tailored for injecting users, such as NSP and OAT. The popularity of injecting among younger people who use psychoactive substances is also decreasing, and the lack of social desirability may lead to denial of injecting drug use and active dissociation from the community of people who inject. Because of the stigma associated with injecting drug use, young injecting users who attend prevention services do not report injecting use to programme personnel until there is a sufficient rapport between the staff and the clients. Thus, the boundaries between injecting and non-injecting use of substances can be quite diluted, and harm reduction services should not exclude non-injecting users.
5. Similarly, non-traditional forms of sexual self-identification are becoming increasingly popular among young people. Sexual relations between men are not necessarily linked to self-identification as MSM. Thus, programmes targeting MSM as a form of identity may not be attractive for such young people. Harm reduction programmes in recreational facilities allow outreach to new segments of key populations, mainly young KP members not integrated into communities with a clearly defined identity.
6. Drug scenes in many countries are characterised by the growing prevalence of ATS and **synthetic cathinones**, which eases and increases the likelihood of **transition to injecting**. Resistance to such transition may weaken in the context of systematic use of methamphetamine or synthetic cathinones, which can be associated with the fast onset of mental disorders. There is evidence that synthetic cathinones are also entering recreational drug scene. The growing prevalence of non-injecting use of easily injectable stimulants makes transition to injecting significantly more likely. One of the important tasks of harm reduction programmes targeting recreational users is the prevention of transition to injecting, as well as the diffusion of harm reduction ideology and skills that reduce the risk of serious harm if the transition to injecting does happen.
7. **Overdose** is less common among non-injecting users than among injecting users but does occur. Community education (along with strengthening the capacity of emergency health services) is the most important strategy in overdose prevention and management. **Fentanyl** has already entered illicit drug markets in many countries, and there is a high probability of fentanyl introduction in other countries. Fentanyl is associated with an increased risk of fatal overdose, especially among stimulant users who do not have access to naloxone and have never experienced an opioid overdose.
8. The relatively low prevalence of HIV infection among the younger, predominantly non-injecting users of psychoactive substances increases the **relevance of HIV prevention interventions** **(including PrEP)** in this population. HIV testing in this group has a prevention effect and a certain potential for **HIV detection**. HIV testing among people who start experimenting with high-risk behaviours (proxy KPs) becomes more relevant as established KPs become well covered by testing interventions.
9. **Sexualised drug use** (chemsex), the use of psychoactive substances to improve or otherwise modify sexual experience, is prevalent among non-injecting users. There is evidence that the use of psychoactive substances in sexual contexts is associated with less safe patterns of sexual behaviour, including **increased likelihood of group sex and reduced use of condoms**.
10. Efforts aimed at nurturing the culture of psychoactive substance use and harm reduction require certain liberalisation of societal attitudes towards the use of psychoactive substances, including among law enforcement. The development of drug checking services will challenge and change law enforcement practices and expand the spectrum of responses to possession of psychoactive substances (depending on the type of substance, the amount, intention to sell, the age of the person, etc.). Decriminalisation of drug use is one of the main conditions for further development and scaleup of harm reduction programmes, as well as for any significant expansion of access to HIV treatment for people who use drugs. Harm reduction education and services for recreational users contribute to more nuanced and objective understanding of substance use and associated phenomena among healthcare specialists, law enforcement personnel and the public, thus forming 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.
11. The development of harm reduction interventions targeting recreational substance users opens opportunities to study and monitor the recreational drug scene, acquire information required for further harm reduction interventions, develop practical outreach work, and effectively respond to new challenges posed by the dynamic drug scene. Studying modern nightlife culture also allows for exploring the opportunities for the diffusion of inclusivity from nightlife EDM communities to the rest of the population.
12. Traditional harm reduction programmes targeting problem drug use predominantly serve older segments of the PWUD population and offer information and services to people at advanced phases in their substance use, characterised by significant deterioration of physical and mental health, chronic diseases and poorer prognosis. **By analogy to the early diagnosis and treatment of HIV infection, offering harm reduction information and services to people at the early stages of their drug use – before health significantly deteriorates and other significant problems emerge – will bring significant benefits in prevention and care**.

The approach to working with the younger people who practice high risk behaviours is radically different from the approach that prevails in our work with classic KPs. 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. Younger KPs (including experimenting young people exploring their sexuality) are not attracted by explicitly HIV or KP-focused services. Still, they can be attracted by objective, sufficiently detailed and unbiased information on areas of interest and by delivering services designed to reduce the risk and harm associated with pleasure-seeking behaviours.

**The methods of work with younger segments of recreational users may include the following:**

* The conceptual postulates of this work should be based on human rights principles and appeal to experimenting young people. Building and retaining rapport with PWUD at the early stages of their substance use will prevent the transition to riskier and more harmful patterns of use and sexual behaviour, as well as HIV infection and other problems associated with high risk behaviours. One example is the concept of Smart Pleasure, utilised by the Ukraine harm reduction project Drugstore.
* The work should use culturally appropriate Internet and social media channels carefully targeted at people who already use psychoactive substances or engage in other high-risk behaviours.
* Meticulous design and branding of communication channels and materials and service delivery platforms need to appeal to the target audience.
* Service delivery and outreach should combine online and offline methods (e.g., at drop-in centres or entertainment venues).
* Services should use appealing harm reduction and HIV prevention commodities field tested with the target audience.
* Studies of substance use and sexual practice should monitor the drug scene and inform interventions and policy development. Field and online surveys can also be used as outreach channels.
* Drug checking is the most popular service among recreational users of psychoactive substances. Programmes should utilise drug checking modalities currently allowed in their locations. On-site distribution and home delivery of colorimetric tests for self-checking by the clients can be utilised in places where collection of samples for further professional analysis is not yet possible. This should be combined with developing feedback channels with due attention to protecting the client’s privacy and ensuring the confidentiality and safety of programme participants.
* Drug checking programmes should contain a strong harm reduction communication component and provide individualised counselling and advice based on the specific risks associated with the use of substances and harm reduction methods.

## Prevention of Overdose

Opioid overdose is the greatest cause of mortality among PWID. Opioid overdose is both preventable and, if witnessed, treatable. OAT 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 does not have psychoactive properties, is easily administered and inexpensive.

## Complementary Services

A rich combination of services address multiple challenges facing key populations to meet basic needs, focus on unprioritised health challenges, strengthen the rapport between providers and clients and increases the attractiveness of prevention and care programmes.

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

* Prevention, vaccination, diagnosis and treatment of viral hepatitis. Viral hepatitis, primarily B and C, adversely affect the health of PWUD and reduce the effectiveness of their participation in prevention and treatment programmes. In particular, hepatitis B and HIV co-infection is associated with faster progression of liver disease and mortality among people with viral hepatitis B and C.
* 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. WHO recommends close cooperation between TB clinics and prevention programmes for PWUD and ensuring unimpeded access of PWUD to treatment at such facilities.

Other important complementary services include:

* 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 OAT patients, as well as HIV testing services.

Involvement of peers is also a basis for successful formative assessment and subsequent monitoring, outreach work and marketing of services. PWID community mobilisation can also be considered a type of psychosocial support (e.g., creation and support of associations of OST patients or ART patients who use drugs). Another dimension of community mobilisation is mobilisation for participation in the development of programmes and preparing decisions n the structure and funding of HIV related activities.

Effective psychosocial support, particularly if delivered by peers, significantly increases the effectiveness of other components of the service package. In addition to that, psychosocial support helps to overcome social isolation, which is widespread in marginalised communities. A number of studies established the connection between social isolation and mortality, particularly among people with chronic diseases (e.g., among patients with cardiovascular diseases)[[4]](#footnote-4).

Other potential areas for CLM include monitoring of funding decisions, funding allocation and funding distribution between various components of HIV related 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 attractiveness and decreasing retention rates, indicating intervention failure.

Enthusiastic civil society programmes, which are well connected and have diverse and elaborate partnerships, can significantly expand the spectrum of offered services. Thus, they can attract and retain more clients and improve intervention effectiveness substantially. If you cannot top-up your service combination and make the programme more attractive with support from partners – find someone who can. Otherwise, you will run an average boring programme with limited effectiveness.

## Structural Interventions

Structural interventions 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 drug scene affecting the processes related to production, distribution and use of drugs, as well as legislative norms law enforcement practices that may inadvertently increase the risk of HIV transmission and prevent the delivery of services. Structural interventions may directly target the negative factors or nurture a supporting environment through so called critical enablers. These include fostering political commitments and support of advocacy activities, revisions and modernisation of laws, policies and practices, community mobilisation and elimination of stigma.

Important areas of structural work include ensuring the required endorsements, partnerships and ongoing coordination with involved stakeholders. Examples include:

* Clearances and agreements with local, sub-national, national health and drug control authority;
* Sensitisation of key stakeholders: e.g., law enforcement, religious leaders, influential organisations, community leaders;
* Specific clearances, endorsement and alignment of working schedules, etc.;
* Coordination with other relevant service providers: alignment of schedules, pooling resources, referral mechanisms and joint monitoring frameworks;
* Selection of implementation agency (relevant experience, sufficient capacity, solution track record, authority in the community, broad partnership network, access to target population, etc.).

Community involvement has already been considered earlier and is crucial for:

* 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

Levers of community involvement vary and include:

* Feedback on services
* Outreach and service delivery (peer models)
* Programme development and management
* Coordination and governance (including membership in advisory and coordination bodies such as CCM)

# Utilised Resources

* FHI 360. Monitoring guide and toolkit for HIV prevention, diagnosis, treatment, and care programs with key populations. Durham (NC): FHI 360, 2020.
* WHO. Consolidated guidelines for HIV prevention, diagnosis, treatment and care for key populations, 2016 update. Geneva: WHO; 2016.
* WHO. 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.
* UNAIDS, PEPFAR, Global Fund. Operational guidelines for monitoring and evaluation of HIV programmes for sex workers, men who have sex with men, and transgender people*.* Washington (DC): USAID (Measure Evaluation); 2013.

1. Community-based monitoring: An Overview, The Global Fund, May 2020 [↑](#footnote-ref-1)
2. Community led monitoring brief [↑](#footnote-ref-2)
3. **Understanding gaps in the HIV treatment cascade in eleven West African countries: Findings from a regional community treatment observatory,** Gemma Oberth, Solange Baptiste, Wame Jallow, Alain Manouan, Pedro Garcia, Anta Mariam Traore, Joelle Murara and Raoul Boka, CSSR Working Paper No. 441, September 2019. [↑](#footnote-ref-3)
4. See e.g. Brummett BH, Barefoot JC, Siegler IC, Clapp-Channing NE, Lytle BL, Bosworth HB, Williams RB Jr, Mark DB. Characteristics of socially isolated patients with coronary artery disease who are at elevated risk for mortality. Psychosom Med 2001;63:267-272. [↑](#footnote-ref-4)