

# UNLEASHING THE POWER OF COMMUNITY:

Community-Led Monitoring and  
Advocacy in CEECA



**Regional Platform**  
EECA

# Regional community consensus consultation on CLM in Eastern Europe and Central Asia

- ▶ Involved 22 community-led networks and various regional civil society organizations
- ▶ Developed a joint vision on CLM definition, principles, and management of conflicts of interest
- ▶ Discussed approaches to ensuring sustainability of CLM initiatives
- ▶ Generated key recommendations for stakeholders and outlined priorities for the Global Fund



# Support Position of Regional Networks on Community-Led Monitoring



# Definition of CLM

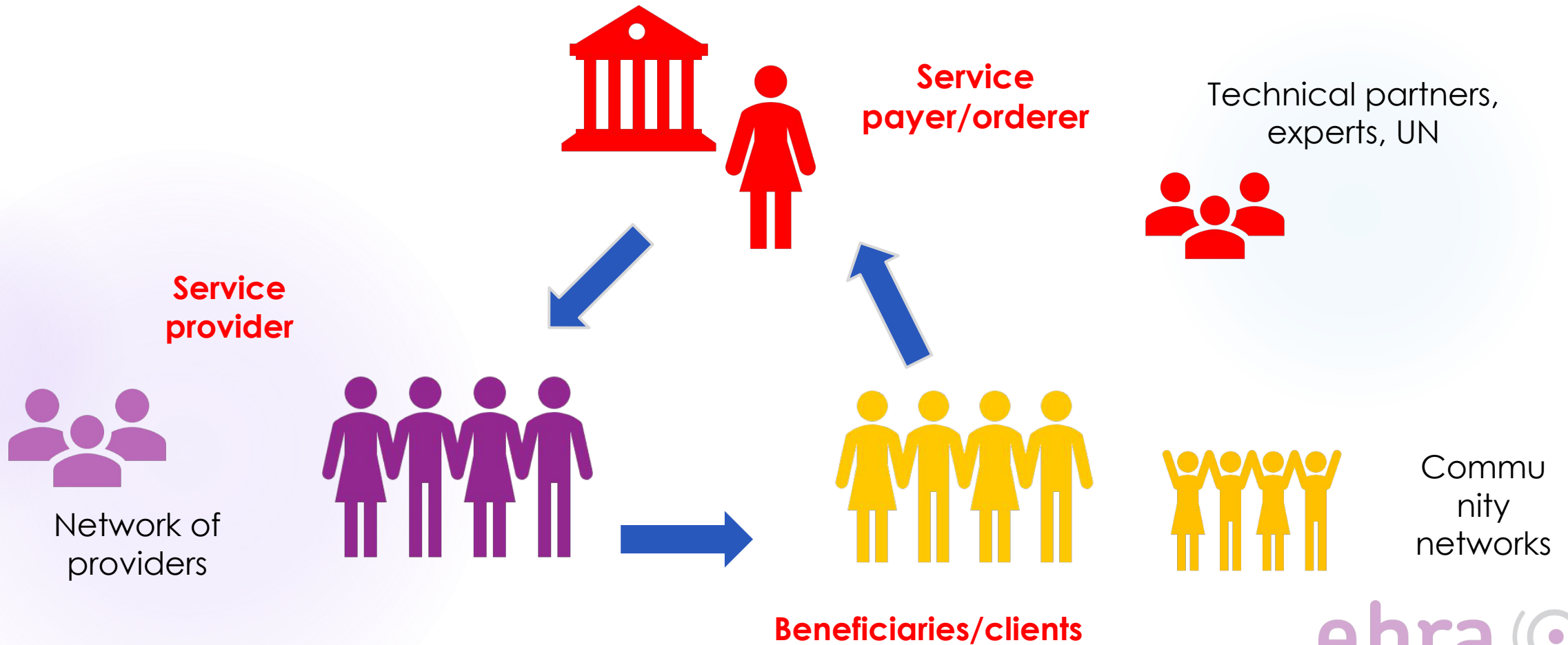
Community-Led Monitoring is **the monitoring of issues, phenomena and processes IMPORTANT TO THE COMMUNITY**, which is carried out by the community and led by the community on an ongoing basis until the desired result is achieved, and in which the fundamental principles of CLM are observed.

The data obtained through CLM is used as **the basis for decision-making in order to achieve positive changes for the community**. CLM is an integral part of community-led advocacy, cohesion, mobilization and strengthening of community systems.

ISSUES AND  
PROCESSES THAT  
ARE IMPORTANT  
FOR THE  
COMMUNITY ARE  
**THOSE THAT  
AFFECT QUALITY  
OF LIFE IN THE  
COMMUNITY**

- ▶ Services
- ▶ Human rights violation
- ▶ Legislation and compliance
- ▶ Policies
- ▶ Systems and practices to address epidemics
- ▶ Stigma and discrimination
- ▶ Gender equity
- ▶ Governmental and other procurement
- ▶ Budget formation and use
- ▶ Program funding
- ▶ Implementation of treatment, diagnosis, prevention and care
- ▶ Other issues, phenomena and processes that communities consider important

# ROLE OF CLM IN SERVICE QUALITY: Who is responsible for the quality of the services?



# Service quality from **PAYER's** perspective



- Assessment based on quantitative indicators (coverage)
- Formal assessment of compliance with norms in relation to finances
- Licensing of social services (in some countries)

## **Challenges**

- No tools for regular quality data collection
- No specialists to assess the quality of such specific services
- Difficulties in assessing the impact of services
- No understanding of why beneficiary assessment and beneficiary self-assessment are needed

# Quality assurance system on the part of the **PROVIDER**



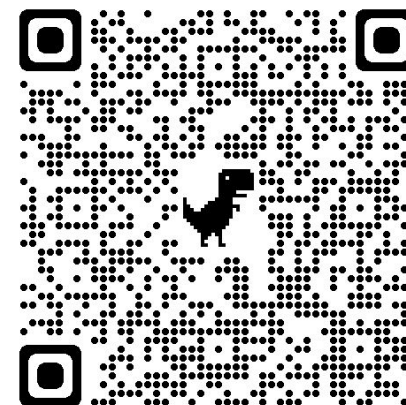
## What we have

- training and supervision of employees,
- internal monitoring
- Customer feedback system (anonymised, without the threat of losing the service)
- Regular review of services based on changing customer needs and feedback

## Challenges

The budget is tight and only for part of the HIV package  
No funds for staff training and supervision  
No comprehensive organizational quality management system in place

## COMPONENTS, ARGUMENTS, CRITERIA OF QUALITY HARM REDUCTION SERVICES





## Service quality from **CLIENTS** perspective



### **Community-led monitoring:**

Assessment of access to services

Assessment of service quality (e.g. mystery shopping, comparison of services with standards – national or international)

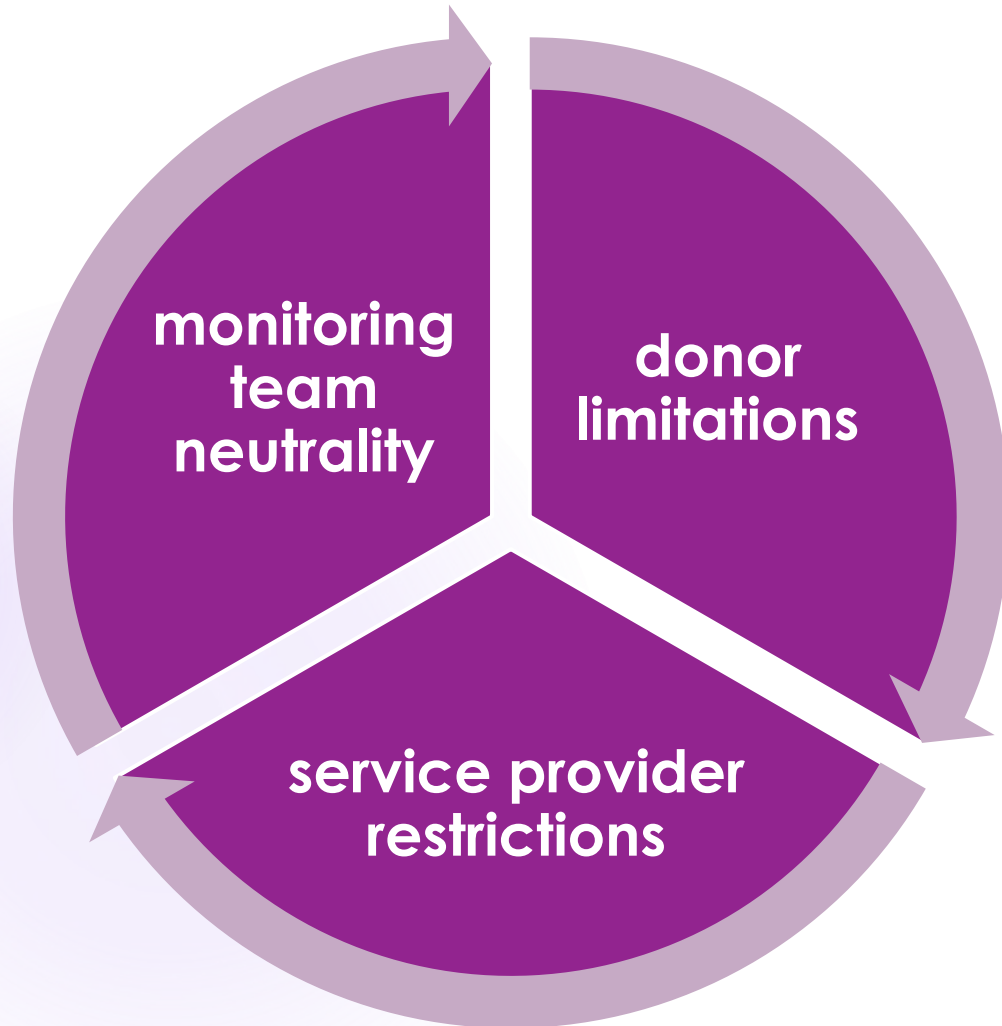
Assessment of the satisfaction with services

Gender audit of services

Documentation of violations of the rights of clients of services



# Managing Conflict of Interest



- Donors can fund CLM, but cannot have a final say over the methods and performers of CLM, or the use of its results;
- CLM that relates to service delivery cannot be conducted by the organizations providing the same services;
- A member of the monitoring team must not have a paid position in the organization that is being monitored;
- Prior to monitoring, there should be an option to form an ethics team;
- Conflict of interest should be declared by the community as well as by the donors.

# Ensuring CLM sustainability

- ▶ Sufficient funding
- ▶ Advocacy resources
- ▶ Community education
- ▶ Legal environment
- ▶ Diversified funding streams

# Stakeholders' responsibilities

Community organizations leading

Government agencies recognizing and using CLM data for managerial decisions

Donors allocating funding and using data for decisions

Regional/global partners ensuring community participation, capacities and support

# Addressing Remaining Challenges and Charting the Path Forward for CLM in the Region

## Challenges

Balancing effective CLM initiatives with adherence to CLM principles

Insufficient community expertise in CLM and further use of data for advocacy

Shortage or absence of financial, human, and technical resources for CLM

???

???

???

## Way Forward

- ▶ Discuss position with donors funding HIV programs
- ▶ Conduct meeting with Global Fund, including CLM Strategic Initiative
- ▶ Learn from M&E experiences in other regions
- ▶ Conduct expanded consultation with community-led organizations in the region
- ▶ Consult with international partners on common CLM definition
- ▶ Explore the possibility of creating a regional CLM working group
- ▶ Capacity building for communities in countries
- ▶ ???



# Accessible Practical Tools for CLM

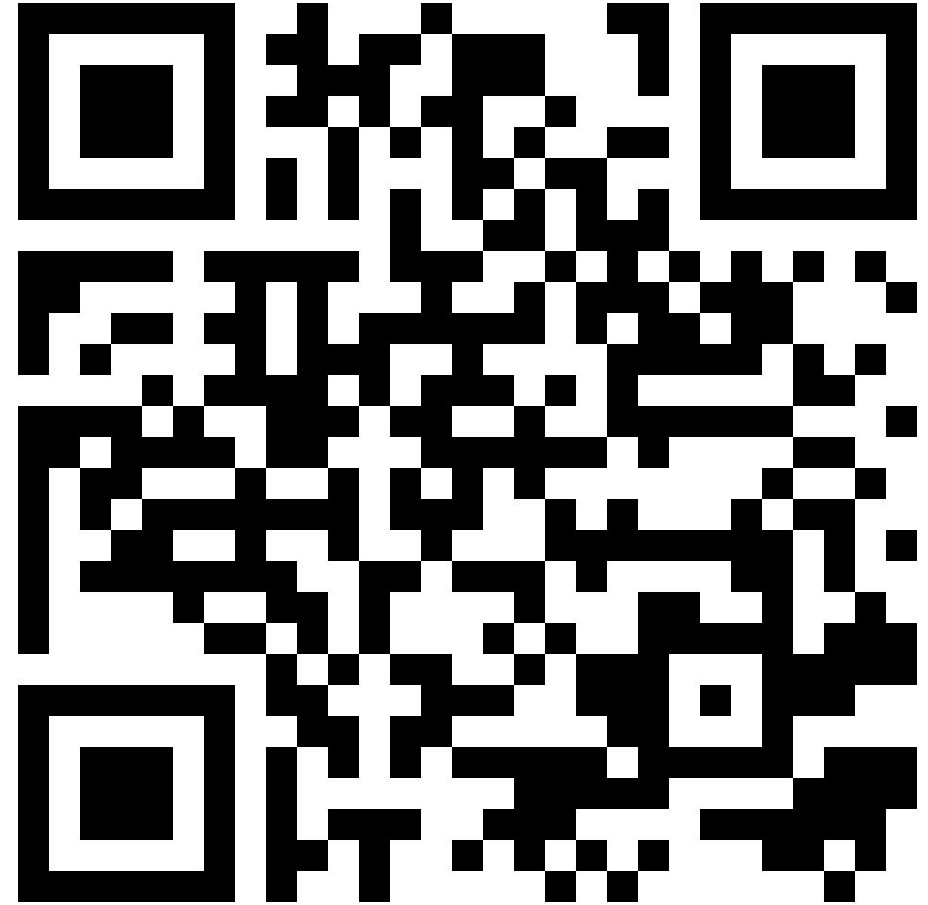
# EHRA's web-tool to select correct monitoring method for successful regular CLM

EHRA's web-tool to select correct monitoring method for successful regular CLM:

Choose the best CLM tool for your community group

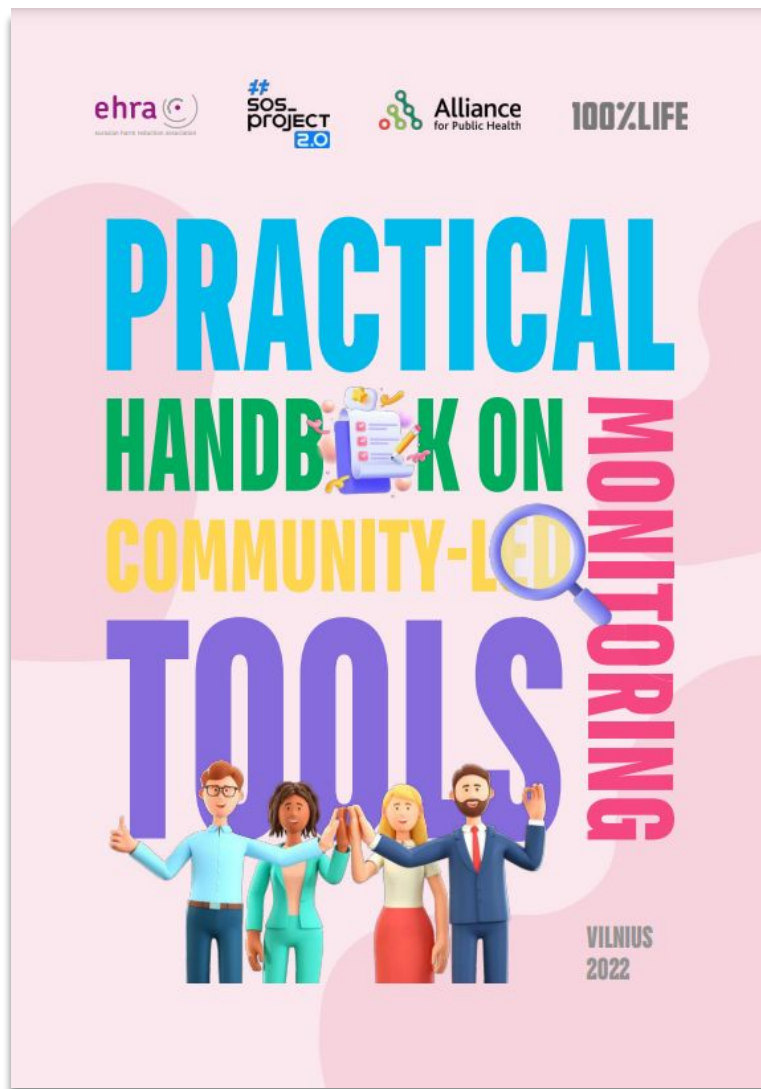
Match collection method to questions and advocacy goals

Assess tool compatibility with available resources (time, finances, human)



<https://harmreductioneurasia.org/clm-tool>





<https://t.ly/exlp>



<https://t.ly/1nyv>



<https://t.ly/tr4Q>



# Exemplary Community-Led Monitoring Practices in Eastern Europe and Central Asia Conducted by Regional Community Based Networks

## CLM OF SERVICES

<b>Subject of monitoring:</b>	Satisfaction/dissatisfaction of clients with the program, maintaining the confidentiality of personal information, and the degree of vulnerability of patients participating in public/private programs.
<b>Method used:</b>	Semi-structured interviews, desk research
<b>Countries:</b>	Belarus, Estonia, Georgia, Moldova, Montenegro, Ukraine.

## CLM OF BUDGET FORMATION AND USE

<b>Subject of monitoring:</b>	Analyzing the allocation and effectiveness of state and municipal budget funds for health and social services targeting key vulnerable groups, such as people living with HIV, PWUD, and LGBTIQ communities.
<b>Method used:</b>	Data collection, desk research, content analysis, Interview, survey.
<b>Countries:</b>	Armenia, Bulgaria, Kyrgyzstan, Romania and Ukraine

# CLM OF HUMAN RIGHTS FOR MSM AND TRANS PEOPLE IN THE REACT SYSTEM



- 240 cases of human rights violations, discrimination, and violence against SOGI registered in 2022
- All monitors are community representatives with a good outreach to the target audience
- Improved REAct system statistics for MSM and trans\* people
- Data included in various reports for UN, OSCE, and Global Fund



# CLM OF LEGAL ENVIRONMENT RELATED TO SOGI AND HIV



- Research protocol developed and approved by community members, as well as data collections
- Systematic data collection and comparative analysis every 2-3 years, according to international standards on SOGI and HIV
- Developed and approved by community members recommendation for the legislation amendments
- Data included in in various reports for UN, OSCE, and Global Fund



## LEGISLATIVE ANALYSIS RELATED TO SOGI AND HIV IN KYRGYZSTAN

2020  
ECOM



## LEGISLATIVE ANALYSIS RELATED TO LGBT RIGHTS AND HIV IN AZERBAIJAN

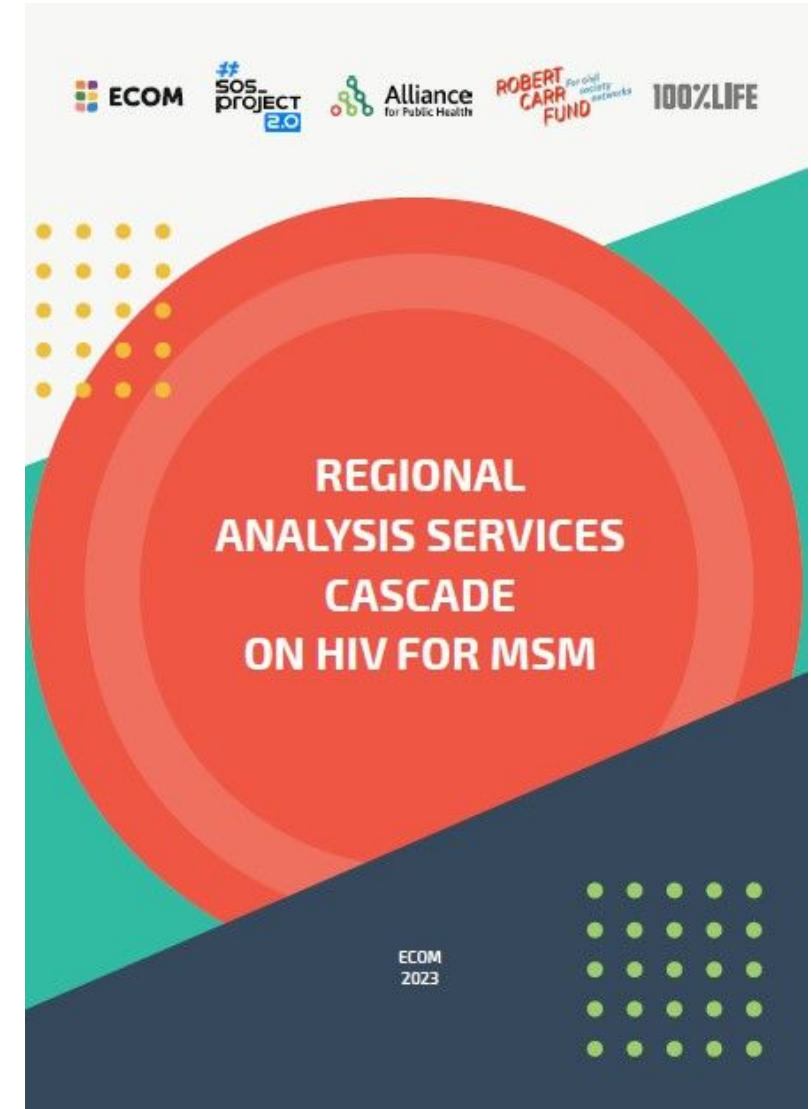
2019  
ECOM



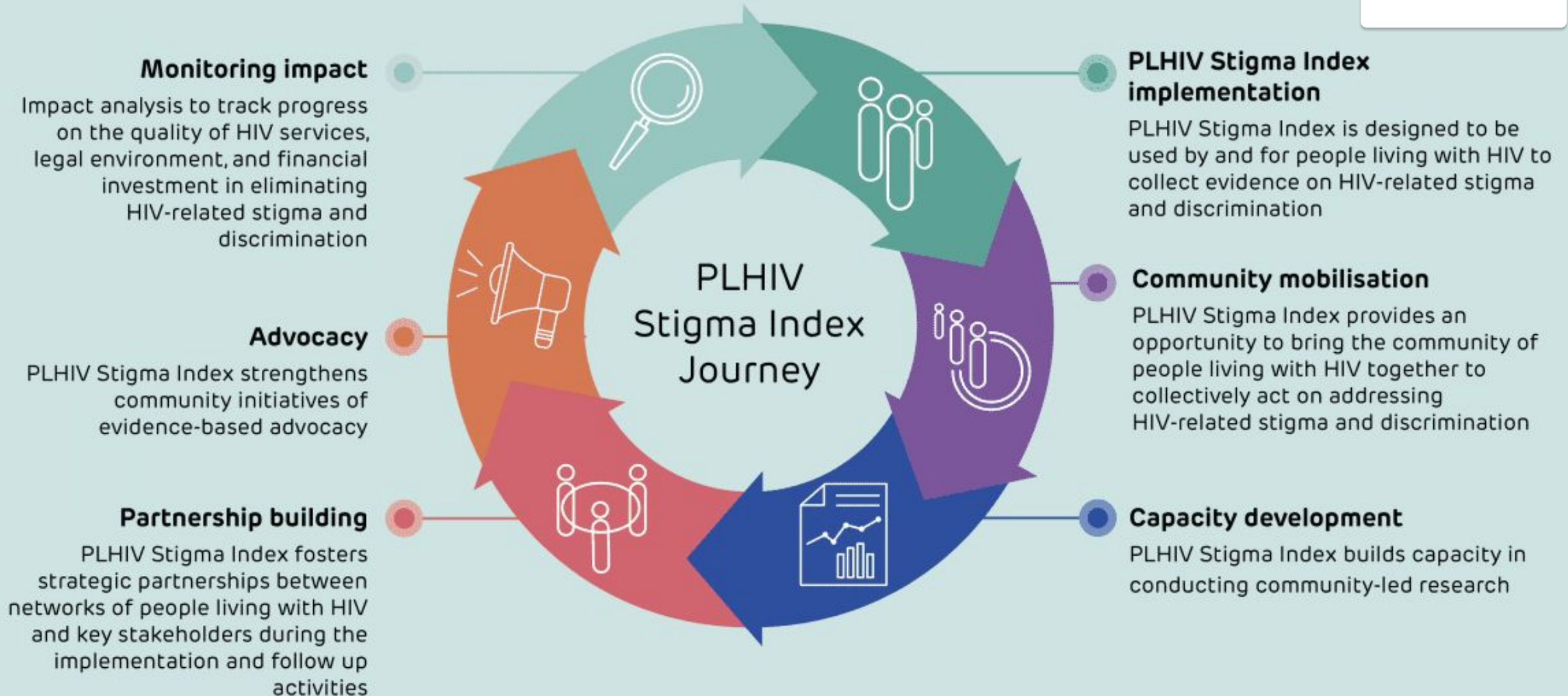
# CLM OF HIV SERVICES FOR MSM AND TRANS PEOPLE



- HIV Cascade Analysis of HIV services for MSM and Trans people - led and implemented by community members
- ECOM keeps HIV-related data among MSM in EECA up-to-date (annual research and updates)
- Population size estimation of MSM and trans people to scale-up national HIV programs
- Regular needs assessments of MSM and trans people to advocacy for adequate access to services



# CLM OF STIGMA AND DISCRIMINATION



# CLM IN TREATMENT, DIAGNOSIS, PREVENTION, AND CARE IMPLEMENTATION

- ▶ Set of websites **(in cooperation with local partners)** to monitor stock outs:

- ▶ [www.pereboi.ru](http://www.pereboi.ru)  
[www.pereboi.kg](http://www.pereboi.kg)  
[www.pereboi.kz](http://www.pereboi.kz)  
[www.pereboi.by](http://www.pereboi.by)  
[www.pereboi.am](http://www.pereboi.am)  
[www.helpiv.ru](http://www.helpiv.ru)

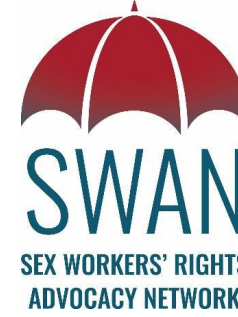
- ▶ HCV, HIV treatment procurement monitoring, monitoring of diagnostics (CD4, VL, DR etc.) procurement

## Key advocacy achievements based on CLM results

- ▶ Increased state budget for HIV treatment in Russia (2012, 2017/18)
- ▶ Lowered ARVT prices in several EECA countries
- ▶ Initiated emergency medication supplies in countries. After the Russian invasion of Ukraine, the websites were used as a source of data to supply antiretroviral medication to people living with HIV.
- ▶ ARVs provided to 500+ PLHIV during COVID in 2020-2021 and war in 2022-2023, including 400+ from EECA countries



# CLM at the regional level



Example: thematic area - human rights violations and legal environment

- ▶ Arrest the Violence: Human Rights Violations Against Sex Workers in 11 Countries in CEECA (2009)
- ▶ Failures of justice: state and non-state violence against sex workers and the search for safety and redress (16 countries, 2015)
- ▶ Sex Work Legal Frameworks in CEECA (2019)

At that time some of these community-led researches and studies were not called CLM.

All regional wide research activities by SWAN are directed by the principle of meaningful engagement of sex workers and aimed to collect and understand sex workers live experience

## Arrest the Violence

HUMAN RIGHTS ABUSES AGAINST SEX WORKERS  
IN CENTRAL AND EASTERN EUROPE AND CENTRAL ASIA

## FAILURES OF JUSTICE

State and Non-State Violence  
Against Sex Workers and  
Sex Workers' Rights

## SEX WORK LEGAL FRAMEWORKS

in Central-Eastern Europe  
and Central Asia (CEECA)

# SWAN members CLM experience



## LEGALIFE-UKRAINE EXPERIENCE

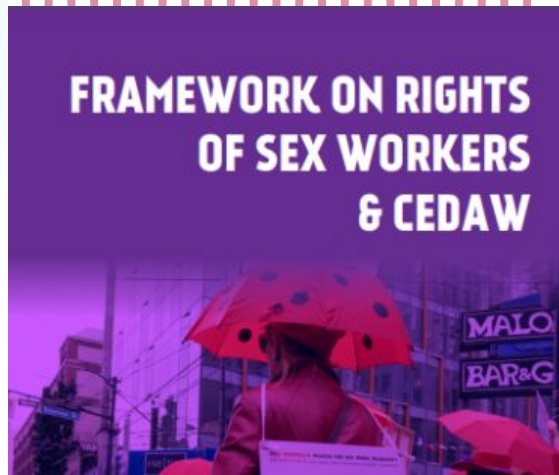
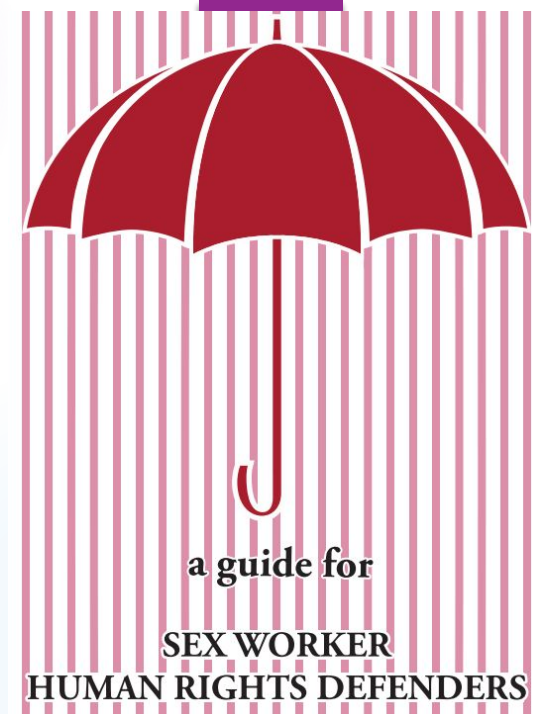
- ▶ Thematic CLM areas
  - ▶ Documenting Human Rights Violations since 2013
  - ▶ Quality of HIV services and barriers
  - ▶ Service accessibility and sex workers needs during the war in Ukraine
- ▶ Methods: different types of interviews, field observation, video documentation
- ▶ Response:
  - ▶ training for sex workers, police, doctors
  - ▶ Awareness-raising and advocacy for decriminalization

## TAIS PLUS EXPERIENCE (KYRGYZSTAN)

- ▶ SWIT is the lens to do CLM: CLM based on SWIT to monitor key areas related to programs with sex workers.
  - ▶ Meaningful engagement at all levels
  - ▶ Violence, human rights and legal environments
  - ▶ Community-led services
  - ▶ Quality and availability of condoms
  - ▶ Medical services
  - ▶ Program management and capacity building
- ▶ Cycling type of CLM due to combining different sources of funding (2016-2022)
- ▶ On the way to routine CLM based on the self-reporting or reports filling in by sex workers with assistance of community activists throughout the year

# CLM tools

- ▶ SWAN guide for sex workers human rights defenders (2014) contains
  - ▶ different models of human rights documenting;
  - ▶ tips on interviewing persons faced with or witness of human rights violation;
  - ▶ tips for writing Human Rights Submissions and Letters;
  - ▶ how to report sex-workers' rights abuses through UN Special Procedures;
- ▶ Experiences and Tips in Community-led monitoring. SWAN members' practice (ready to issue soon)
- ▶ Tools with advocacy focus developed with SWAN participation
  - ▶ Framework on Rights of Sex Workers & CEDAW
  - ▶ Shadow Report Guidelines on CEDAW & Rights of Sex Workers



**SHADOW REPORT  
GUIDELINES ON CEDAW &  
RIGHTS OF SEX WORKERS**

# EWNA CLM Sexual and Reproductive Health and Rights of Women Living with HIV

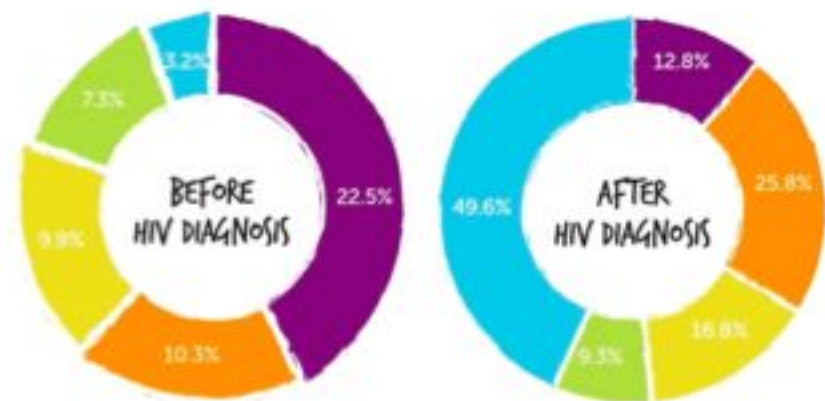


**The goal** is to identify the key issues and needs of women living with HIV related to sexual and reproductive health through the prism of human rights.

Experiences and challenges in various aspects of the day-to-day life of women living with HIV in the field of sexual and reproductive health and other areas:

- healthy sex life,
- pregnancy and fertility,
- violence and discrimination against HIV-positive women,
- mental health and HIV,
- burden of family caregiver,
- HIV treatment and side-effects,
- economic opportunities and access to social services.

EECA countries: Ukraine, Moldova, Belarus, Russia, Kazakhstan, Tajikistan, Georgia, Serbia,



## VIOLENCE AGAINST WOMEN

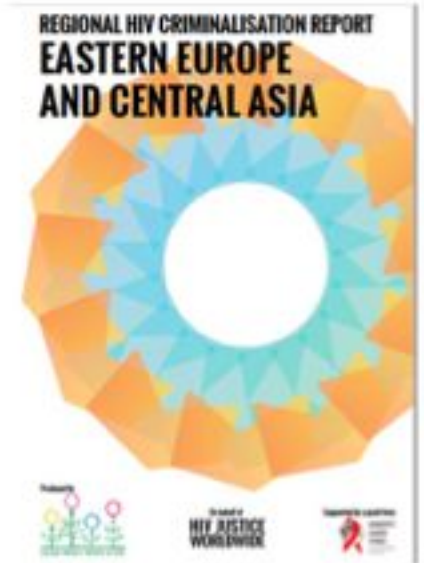


# EWNA CLM HIV Criminalisation Scan in EECA (2018, 2022)

Principles: **Inclusion and Leadership. Safety. Gender optics.**

The methodology includes selection and contracting of country informants from among the EWNA members for the following activities at the country level:

- collecting information about laws that criminalise people living with HIV;
- making inquiries to public authorities;
- documenting cases of HIV criminalisation, including blackmail;
- describing advocacy activities aimed at HIV decriminalisation;
- media monitoring.



## EWNA CLM

# Monitoring of types of violence against women living with HIV

including factors preventing support/help seeking behavior for women living with HIV who experience violence

*Goal* : to identify the key characteristics of violence against women living with HIV and the specifics of organising assistance for women living with HIV who have experienced violence.

The main *objectives* :

- examine women's personal assessments of their lived experience of gender-based violence, including **physical, psychological, economical and sexual violence**.
- examine the experiences of women who seek and those who do not seek assistance.
- examine the specifics of organizing assistance, including access to shelters, for women who have experienced violence.
- analyse existing barriers to receiving assistance.



# Implementation

## Digital system



Mobile app



Infoboxes



Dashboard

## Projects with involvement



Community activists



Paralegal services

# Services and Data Collection



Consultation and  
help by phone



Humanitarian  
help

We provide clients with a wide range of assistance. In parallel with this, we are forming an evidence base that includes personal data for verification and the barriers faced by people with tuberculosis.



Psychological  
self-help module



Legal aid



Expert help

This way of working allows us not only to monitor barriers, but also to partially cover the needs that arise in the community. In this way, we also motivate people to participate in the monitoring process, since the provision of help has a positive effect on people's trust in the organization.



Help with  
medication and  
diagnostics



# Advocacy and fundraising

A national expert group works on the advocacy process in the organization, which deals with the solution of systemic barriers to the treatment of tuberculosis, which were identified and confirmed as part of the monitoring. Representatives of the organization fight for appropriate legislative and practical changes at the highest level to eradicate practices that violate people's rights and systemic barriers to recovery.

The continuity of the monitoring process is an important component of its success and relevance. At the moment, all processes related to the implementation of SLM are financed by international donors, which is potentially risky for the continuity of funding.



# CLM in prisons

- Limited access to data in penitentiary systems
- Limited possibility to collect data among prisoners
- Absence of standardized approached to collecting data in closed settings

1

HIV/TB prevention, care and support projects

2

National preventive mechanisms

Oversight commissions

3

Digital solutions



## ROADMAP ON IMPLEMENTATION OF CLM IN PRISONS OF ECA REGION

- Guideline for conducting CLM in prisons for CBOs, penitentiary systems, prison administrations



General principles  
of CLM in prisons



Data to be  
collected and  
mechanisms of  
collection



Legislative and  
infrastructural  
conditions for data  
collection and usage



Suggestions on  
data institutionalization



## **HAC's vision of community-led and community-driven monitoring, which formed the core of the implemented projects**

- The CLM is a central component of sustainable health systems that is able to provide rapid feedback on performance and respond effectively.
- The CLM enables the coordination of response mechanisms that eliminate barriers to accessing health system services, making them more relevant to the real needs of patients.
- The CLM complements the national health management system and reduces structural, social and legal barriers to health services and improves the efficiency of these services.
- The CLM is able to provide a mechanism of public control and accountability of the health care system and HIV/TB programs, which are aimed at achieving the health indicators - 95-95-95, 10-10-10, other health indicators of importance for health protection.

## **Визия НАС относительно мониторинга силами и под руководством сообществ, которая лежит в основе реализованных проектов**

- MPC является одним из центральных компонентов устойчивых систем здравоохранения, который способен быстро давать обратную связь о работе и эффективно реагировать на нее.
- MPC позволяет координировать механизмы реагирования, которые элиминируют барьеры в доступе к услугам системы здравоохранения, делая их более соответствующих реальным потребностям пациентов.
- MPC дополняет национальную систему управления охраной здоровья и позволяет снизить структурные, социальные, правовые барьеры к услугам охраны здоровья, а также повысить эффективность этих услуг.
- MPC способен обеспечить механизм общественного контроля и подотчетности системы здравоохранения и программ по ВИЧ/ТБ, которые направлены на достижение показателей охраны здоровья - 95-95-95, 10-10-10, других значимых для охраны здоровья показателей.



## HAC's key areas of work regarding the development of CLM practices

### (1) Strengthening community capacity in CLM

- a. Building the evidence base for further strengthening communities in CLM - mapping community capacity and issues in CLM in Kazakhstan, Kyrgyzstan, Tajikistan, Moldova and Ukraine (HAC methodology in partnership with Oxford University team).
- b. Ensure stakeholder coordination on improving the capacity of organizations to implement the CLM by creating, agreeing and ensuring the implementation of relevant national roadmaps in Kazakhstan, Kyrgyzstan and Tajikistan.
- c. Increase the knowledge of Central Asian community organizations regarding aspects of the CLM implementation that were identified by the mapping as needing development (CLM tools, analysis and use of data for advocacy).
- d. Expert and technical assistance in the development of a list of performance indicators, standardization of CLM tools, and expansion of donor funding for its implementation, including GC7 applications in Kazakhstan, Kyrgyzstan, Tajikistan, Ukraine, Moldova and PEPFAR application in Kazakhstan. Funding allocated for the implementation of the CLM in these countries in aggregate exceeds 500 thousand dollars.

## Ключевая направления работы HAC относительно развития практик MPC

### (1) Усиление потенциала сообществ в CLM

- a. Создание доказательной базы для дальнейшего усиления сообществ в проведение MPC - картирование потенциала и проблематики сообществ в проведении MPC в Казахстане, Кыргызстане, Таджикистане, Молдове и Украине (методология HAC в партнерстве с группой при Оксфордском университете).
- b. Обеспечение координации стейкхолдеров относительно повышения потенциала организаций для проведения MPC путем создания, согласования и обеспечения реализации соответствующих национальных дорожных карт в Казахстане, Кыргызстане и Таджикистане
- c. Повышение способности организаций сообществ Центральной Азии относительно аспектов реализации MPC, которые были идентифицированы картированием как нуждающиеся в развитии (инструменты CLM, анализ и использование данных для адвокации)
- d. Экспертная и техническая помощь в разработке перечня индикаторов результативности, стандартизации инструментов MPC, а так же расширении донорского финансирования на его проведение, в т.ч в заявки ГФ GC7 в Казахстане, Кыргызстане, Таджикистане, Украине, Молдове и заявке PEPFAR в Казахстане. Финансирование, алоцированное для реализации MPC в этих странах совокупно превышает 500т долларов.



## HAC's key areas of work regarding the development of CLM practices

(2) Use of CLM data and its integration into national monitoring and evaluation systems for HIV and TB responses

a. Ensure coordination between national level stakeholders on strategic decision making on CLM issues, and include community representatives, government bodies and international agencies. The interdepartmental working group has been established in Ukraine under the MOH PHC, under CCM approval in Kazakhstan, Kyrgyzstan and Tajikistan.

b. Formation of a logical framework for further integration of CLM tools for quality and completeness of HIV-related service packages into the national system for monitoring the quality and completeness of social and health services provided.

## Ключевая направления работы HAC относительно развития практик MPC

(2) Использование данных MPC и его интеграция в национальные системы мониторинга и оценки мер в ответ на ВИЧ и ТБ

a. Обеспечение координации между партнерами на национальном уровне относительно принятия стратегических решений по вопросам MPC, и включают представителей сообществ, государственных органов и международных агентств. МРГ создана в Украине при ЦГЗ МОЗ, на утверждении СКК в Казахстане, Кыргызстане и Таджикистане.

b. Формирование логической рамки для дальнейшей интеграции инструментов СЛМ качества и полноты наборов услуг, связанных с ВИЧ, в национальную систему мониторинга качества и полноты предоставляемых социальных и медицинских услуг.

**WHEN THE  
COMMUNITY  
COMES  
TOGETHER,  
ANYTHING IS  
POSSIBLE!**

