COMMUNITY-LED MONITORING. NPOs' VIEW

Findings of a Survey among NPO Representatives Working in the Field of HIV in Kazakhstan, Kyrgyzstan and Tajikistan

Health Advocacy Coalition
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Disclaimer:

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The conclusions and recommendations contained in this report reflect the views of the authors, which may differ from those of other stakeholders.

The information contained in this report reflects primarily the opinions of the respondents/participants in the study and the country consultations. The Health Advocacy Coalition does not guarantee a 100% accuracy of the data provided by third parties and may have other opinions than those of third parties cited in the report.

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When using data from this document, reference to the source is mandatory. Recommended citation format: "Community-led Monitoring. NPOs' View. Findings of Survey in Three Central Asian Countries. Prepared by the Health Advocacy Coalition, with the Support of UNAIDS in 2022."

List of Abbreviations and Acronyms

- ART - Antiretroviral therapy
- HIV - Human immunodeficiency virus
- WHO - World Health Organization
- PrEP - Pre-exposure prophylaxis
- CLM - Community-led monitoring
- M&E - Monitoring and evaluation
- MOH - Ministry of Health
- U=U or Undetectable = Untransmittable
- NPO - Non-profit organizations
- UNAIDS - Joint United Nations Programme on HIV/AIDS
- COVID-19 - Coronavirus Disease 2019
- PEP - Post-exposure prophylaxis
- CCM - Country Coordinating Mechanism
- PPE - Personal Protective Equipment
- TB - Tuberculosis
- CDC - Centers for Disease Control and Prevention
- CEDAW - Convention on the Elimination of All Forms of Discrimination against Women
- PEPFAR - U.S. President's Emergency Plan for AIDS Relief

Introduction

Community-led monitoring (CLM) is a process in which communities, especially people using health services, take the lead in identifying and regularly monitoring issues that are important to them. They create indicators to track priority issues, undergo training in data collection and outcome analysis, and interact with a wider group of stakeholders to share ideas based on the data collected and jointly develop solutions. If problems identified in the course of CLM cannot be solved, communities conduct fact-based awareness-raising campaigns until responsible persons take remedial action. CLM also documents positive innovations and good practices that can be implemented more consistently and on a larger scale (for more information and definitions of CLM, see the *Guide to CLM*).

Community-led monitoring leverages the resources of people living with HIV and key populations to transform information on health systems into vital campaigns. CLM quickly generates data on HIV prevention and treatment services and enables communities to use the obtained data in order to identify and advocate for solutions that remove barriers to human rights, better health and better quality of life.

CLM is an integral part of the Global HIV/AIDS Strategy 2021-2026, which puts people at the centre of the HIV response measures and brings together countries, communities and partners to achieve the following goals:

1. Maximizing equal and equitable access to comprehensive, people-centred HIV services.
2. Overcoming legal and societal barriers to achieving results in HIV response.
3. Fully resourcing and supporting HIV responses and integrating them into health, social security and humanitarian aid systems.

When problems identified by CLM cannot be solved, communities run evidence-based advocacy campaigns until those responsible take appropriate remedial actions. CLM also documents positive innovations and efficient methods that can be implemented in a more consistent manner and on a larger scale.

Keen demand for and interest in the implementation of CLM require consistent and clear principles. A high-quality CLM and associated advocacy must meet the following principles[1]:

- Led by communities and owned by communities
- Action-oriented, accountability
- Independence
- Performed regularly and systematically
- Result-oriented

[1]Based on the materials from the portal on CLM http://clm.itpcglobal.org/

The current definitions and characteristics of CLM provided by UNAIDS, the Global Fund, PEPFAR, other international donors and various community organizations may vary somewhat, introducing some ambiguity at the level of implementation and leading to different interpretations of the CLM concept at the level of community organizations in the EECA region. An additional factor contributing to the difference in approaches to defining and implementing CLM in the EECA region is the lack of guidance materials on the subject in the languages of the countries of the region, as well as the lack of broad and uniform experience in documenting CLM initiatives.

In general, the existing materials and approaches of international organizations agree that CLM must meet the principles described above. Consequently, CLM implementation activities must not depend on or be led by governments or donors or sponsors. They are specifically designed and conducted by communities and their organizations, groups and networks. They are also collaborative in nature and are aimed at involving various stakeholders in jointly creating and implementing solutions, rather than at blaming anyone.

In this regard, as part of a project supported by the Joint United Nations Programme on HIV/AIDS, the Health Advocacy Coalition conducted in July-September 2022 a survey to assess the level of awareness about CLM and to document problem areas and successful experiences among representatives of the community involved in HIV epidemic response in three countries of Central Asia: Kazakhstan, Kyrgyzstan and Tajikistan, as well as the potential for further development of CLM in the region.

Interviews with representatives of non-profit organizations working in the field of HIV were chosen as a method of the study. The preparatory phase of the study included organizational arrangements, adaptation of questionnaires, selection of respondents, determining the interview format, establishing the acceptable conditions for the participation of respondents, and preparing the interview schedule in coordination with respondents.

The field study was conducted from August 1 to September 30 and was divided into 2 stages:

1. Surveys among representatives of country NPOs by the semi-structured interview method between August 1 and August 30, 2022 (the questionnaire can be found in Annex 1).
2. Consultations in each of the countries under study between September 10 and September 25, 2022.

A total of 51 NPOs were interviewed, with the following breakdown by country:

- Kazakhstan – 19 NPOs
- Kyrgyzstan – 22 NPOs
- Tajikistan – 10 NPOs.

In isolated cases, a number of country interviewers also interviewed representatives of international organizations. However, to ensure sample

integrity, the response of the representative of an international organization was withdrawn from the responses. The list of the respondents is available in Annex 3.

The survey findings are described in three country reports and in this regional summary report.

Besides, an analysis of institutional and legal barriers to CLM implementation was carried out in the three countries, the findings of which are presented in a separate report.

Key Conclusions and Recommendations

Conclusions:

1. 96% of NPOs in the countries under study encountered CLM to varying degrees. At the same time, only 74% were able to give a definition and have formed an idea of the concept itself. However, a detailed survey shows that only a third of the surveyed community representatives confidently use the concept of CLM.

2. The main sources of CLM funding in a country are international donors, of which the vast majority of the respondents in all the three countries mentioned the Global Fund (through country and regional grants), PEPFAR and USAID as the key sources.

3. None of the respondents mentioned public funding (either in direct or indirect form, including in the form of supporting the statutory activities of the organizations) as a source of support for CLM work, which leads to the conclusion that there is no such funding or that information about it is not available to the community organizations.

4. Most respondents do not accurately assess the difference between service project M&E and CLM. More than 60% of the respondents in all the countries consider as CLM various projects aimed at assessing the efficiency of implementing various donor-initiated projects, and occasional studies using a methodology.

5. There is no detailed understanding among the respondents in all the countries as to the possibilities of practically applying the monitoring results or promoting the results obtained.

6. Besides, most of the respondents (82%) noted in one form or another the lack of skilled professionals in conducting CLM, which is one of the key factors of the impossibility of a broader and more efficient CLM in a country.

7. Of particular note is that none of the respondents mentioned any CLM findings presentation in the media or any development of own channels for communicating the results of such work using modern digital technologies (social networks, etc.).

Recommendations

1. Distribution of materials. A number of international organizations and regional networks are currently developing materials on CLM in Russian. Such and similar materials should be widely disseminated to NPOs and community organizations.

2. Training. Training activities on CLM should be held in the countries under study, focusing in particular on the practical application of CLM and advocacy results on the basis of the data obtained.

3. Building the capacity of CLM implementation partners. Investing in training and strengthening the institutional systems of civil society organizations is critical to enabling CLM implementation.

4. Feedback and data dissemination mechanisms should be established to implement advocacy results. It is necessary to work on organizing and maintaining national CLM coordination platforms, where solutions can be jointly developed to address gaps in treatment and services and improve quality, or to integrate CLM coordination into existing country platforms.

5. Funding and investment in CLM. Sufficient funds should be made available for implementing CLM and related advocacy activities. The scale of the CLM approach should be consistent with the available budget (the budget should depend on the number of goals and indicators chosen).

6. At the same time, given the keen interest shown by donors in CLM recently, ethical frameworks and mechanisms should be created to ensure that CLM is indeed community-led and supported by national and international organizations.

7. Integration of the CLM approach into a country's national strategic plans or other national policy frameworks or investment plans. CLM must be adopted as the key community-based method to facilitate national-level responses. To that end, the institutional and legal barriers identified must be overcome. Free access to data should play a key role in this, including in some non-personalized form in medical institutions (more information is available in the report on legal and institutional barriers).

8. Key donors and international organizations must take a number of steps to harmonize the approach to CLM and develop a code of support that will exclude any influence of donor or international institutions' country or regional representatives on organizing the CLM activities.

9. Information on a unified approach to CLM that can meet the needs of representatives of the community of PLHIV, TB and key populations should be promoted.

10. NPOs' motivation to participate in CLM should be boosted. Information on the effectiveness of monitoring as one of the levers of influence on a particular situation should be disseminated.

11. A dialogue should be established between the public sector and NPOs to ensure efficient CLM as one of the tools for solving problems affecting all stakeholders.

12. The number of skilled professionals capable of coordinating the process of monitoring and conducting a follow-up advocacy campaign should be increased.

How CLM is Understood by Country NPOs

As a number of CLM initiatives are being implemented among the international community, differing definitions are being used and there is a shortage of materials on this subject in Russian, we had to find out during the survey the respondents' level of understanding, including the most basic concepts.

When interviewed, the vast majority (74%) of the respondents answered that this is "an activity of monitoring the availability and quality of services carried out by community representatives themselves" (general definition). 34% of them also expanded this concept to include drug procurement monitoring and budget monitoring and advocacy. 14% of interviewees were able to give examples of CLM work. At the same time, it should be noted that only 20% of the respondents indicated that CLM "should influence the development of community-led solutions and actions to overcome barriers."

Figure 1 shows the summary statistics of the respondents for 3 countries.

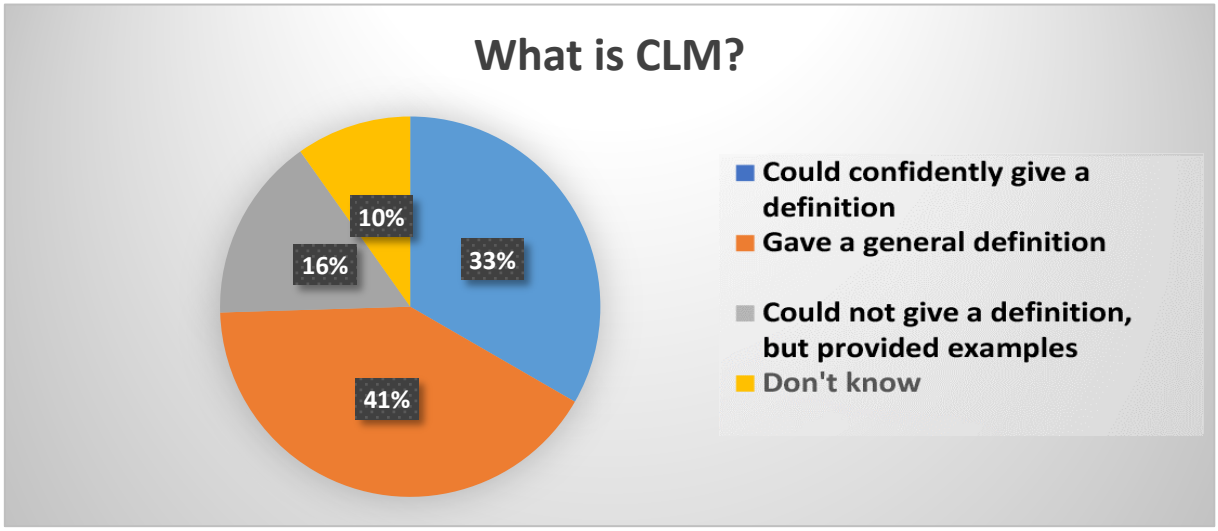

Figure 1

Involvement in and Focus of CLM

«…The fact that monitoring must be carried out regularly is wonderful.

But answer me, how to do it without funding?

And who of donors would want to support

what we need, not what they need?.."

A participant of a consultation

As part of the interviews, representatives of community organizations were asked whether they believed that their organizations were engaged in implementing CLM programs (Fig.2).

47% of the respondents (24 organizations) from the 3 countries reported that their organizations directly implemented such programs. Examples of such programs given by the respondents included the following initiatives:

- OneImpact
- REAct
- Stigma Index
- Drug Procurement and Diagnostics Monitoring
- Pereboi Websites
- Routine Monitoring of Programs
- Mystery Customer Visits

Another 34% of the respondents said that they were involved in the implementation of such programs from time to time. As examples of partial involvement in CLM programs, respondents mentioned the work of obtaining information from community representatives when alternative/shadow reports were prepared or as researchers from the community.

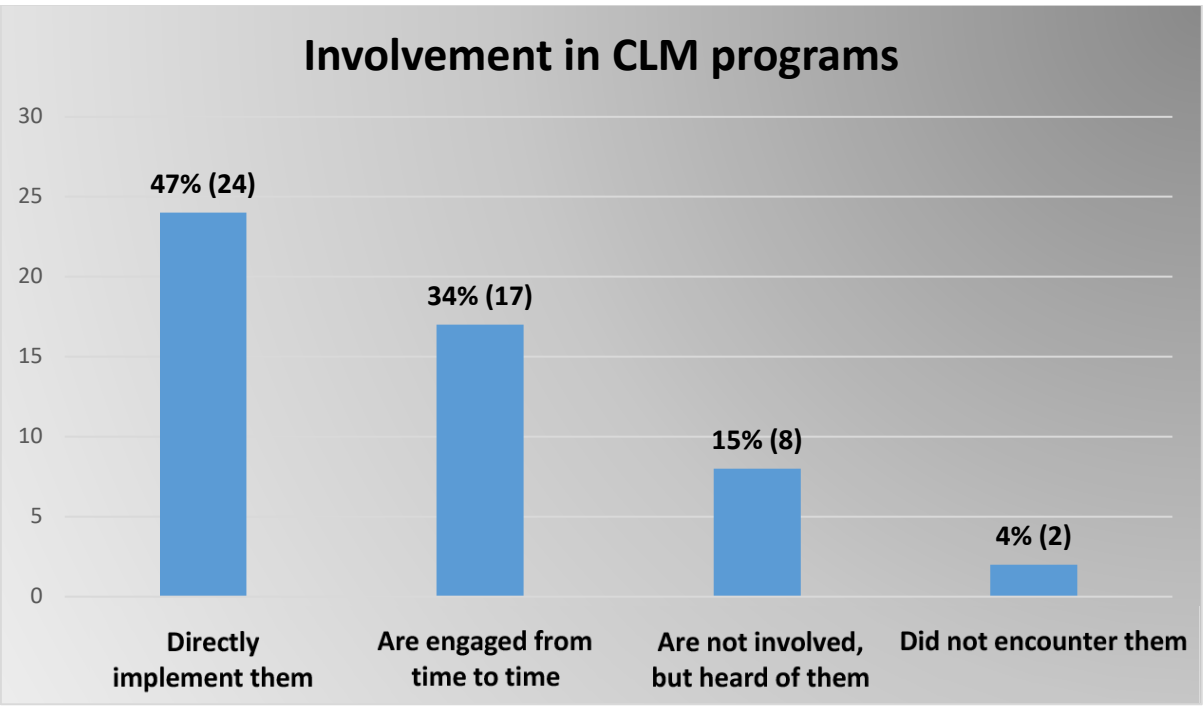

Figure 2

In the context of the foregoing, it should be noted that in terms of data collection regularity, which must be an integral part of CLM, examples such as alternative reporting and donor-initiated research, or research and projects in which community representatives have not been involved in setting priorities, cannot be fully qualified as CLM.

The tendency to qualify such projects as CLM was observed in more than 60% of the respondents. The fact that the respondents qualify such projects and initiatives as CLM further confirms the need to train community organizations in CLM in Russian and national languages, as well as the need to create, translate and distribute written training materials among NPOs.

Of the remaining respondents, 15% were not engaged in any form of CLM, but had heard about such initiatives and programs. 2 respondents (4% of the interviewees) did not encounter any CLM initiatives.

In addition, as part of the survey, a generalized map of successful areas and bottlenecks in the field of CLM was prepared based on the results of respondents' responses processing, including such key areas as HIV transmission paths (raising awareness among young people and the general population), HIV prevention, HIV testing, HIV treatment (including diagnosis), adherence to treatment, drug resistance, monitoring and management of side effects, co-infections (hepatitis, tuberculosis), human rights and the right to health (including stigma and discrimination), funding HIV programs, and the specific needs of key groups. Judging by the answers, the most problematic areas for implementing CLM are the issues of raising awareness among young people and the general population, funding HIV programs, and specific needs of key groups. A detailed table is presented in Annex 2.

Presentation of CLM results

"…It is important to consider how officials may respond to data if there is no approved mechanism for submitting them. How will they react to the data? By the way, the mechanism of data submission and response to CLM can be fixed through CCM..."

A country consultation participant in Tajikistan

"… We must involve supervisory authorities more actively to implement the monitoring recommendations (such as the Ombudsman's Office and so on) and must include the data in various shadow reports and CEDAW…"

A country consultation participant in Kyrgyzstan

Since one of the key aspects, if not the most important aspect of CLM is the use of data in the subsequent advocacy of systemic change for the benefit of the community at the local or national level, a goal was set by us in the survey to examine what tools are utilized by NPOs in the countries to use the data obtained.

The participants were asked to answer an open-ended question, the answers to which were grouped into the categories indicated in Fig. 3.

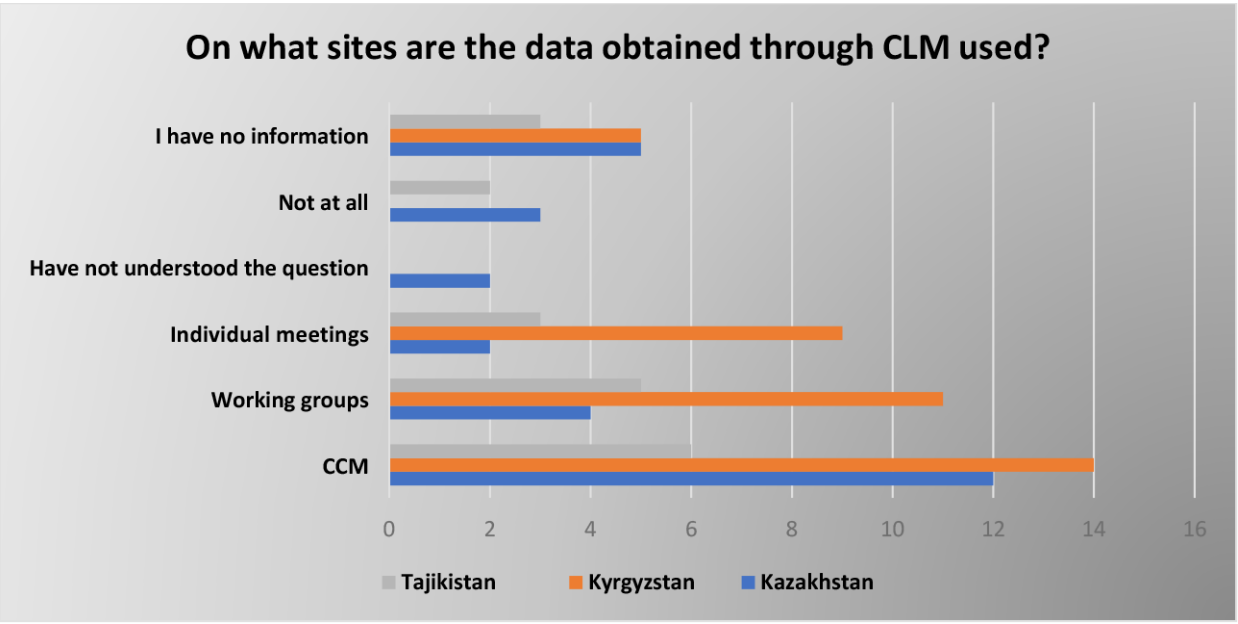

Figure 3

Predictably, the majority of the respondents indicated working with the CCM as the primary data presentation mechanism. The second place was given to working groups and individual thematic meetings. Representatives of ministries and international organizations were indicated as discussion participants in such meetings. Most often were mentioned representatives of:

- The health system (including chief physicians)

- The Ministry of Finance
- USAID
- PEPFAR
- UNAIDS managers

At the same time, there is a noticeable proportion of those who do not have any information on where monitoring results are used or are under the impression that these data are not used anywhere.

None of the interviewees indicated media as a platform for promoting or using the data. Community representatives need to develop the skills of working with traditional media and modern methods of providing information through social networking websites.

In the context of community-led monitoring, community organizations should have a clear understanding that they can and should act as initiators of newsbreaks at the local and national level. To do this, organizations and HIV activists must have the necessary competencies or information on how they can be cost-effectively engaged from outside.

What Problems can be Solved using CLM?

When answering this question, the interviewees could offer many options of answers, which were then grouped together.

Most respondents mentioned stigma and discrimination against key groups in the provision of services by public authorities (including health facilities) as the most important issues for using CLM as the solution. More than 55% of the study participants expressed this view in one form or another.

About 40% of the interviewees noted that CLM created opportunities for determining the need for services and the introduction of new services. 32% of the respondents noted that CLM created opportunities for improving the dispensing of medicines and diagnostics.

Among other health issues that civil society representatives felt could be influenced by CLM, the respondents indicated the following:

- provision of medical services and arrangement of services on the "one-stop-shop" basis - 31%
- tracking the services for key populations in emergencies - 29%
- monitoring the situation with HIV criminalization - 22%
- solving problems in obtaining HIV services at the place of residence - 22%
- improving the quality of diagnostics and access to the required drug supply - 22%.

Who Funds CLM

When answering this question, the respondents could name all donors they know.

In all the countries, the Global Fund, PEPFAR and USAID were indicated as the key donors supporting CLM work (see figure 4).

At the same time, more than 50% of the respondents did not understand the funding distribution structure in the EECA region, and so the Alliance for Public Health (Ukraine), which used a regional grant of the Global Fund, was named among the most significant donors. Further clarification revealed that it was the activities of this project, such as ReACT, that were referred to.

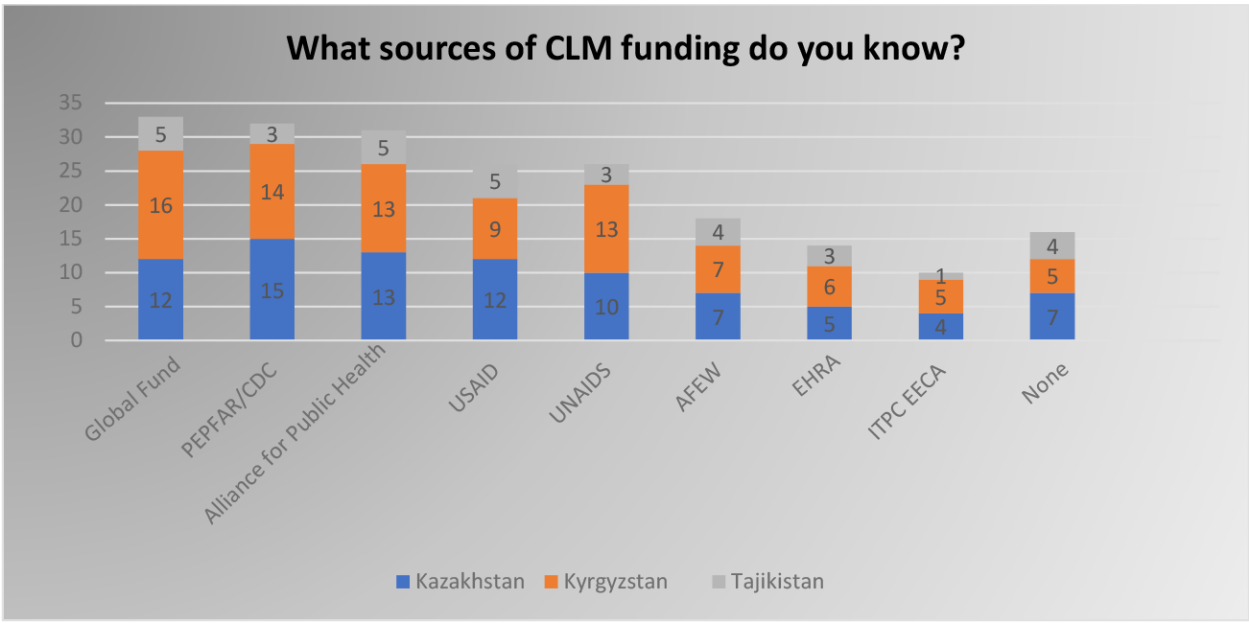

Figure 4

Regional organizations and initiatives with which they have an established connection or in which they had been directly involved were most frequently mentioned by the respondents. For example, AFEW in Kyrgyzstan noted their OneImpact platform implementation project and the community-led monitoring project they were currently implementing with PEPFAR funds through CDC.

The respondents also mentioned the ITPC EECA projects for community-led monitoring of access to treatment and diagnostics, and projects of the Kazakhstan Union of PLHIV, EHRA, UNAIDS, the Global Network of Sex Workers and the Elton John Foundation.

Mostly, the respondents could not answer in detail about the activities of these initiatives, unless they themselves were engaged in their implementation, describing them only in general terms. This suggests that both intra-country and inter-country exchange of information in the field of CLM should be encouraged.

At the same time, one third of the interviewed NPO representatives in the countries could not name any source of funding for CLM initiatives, which also suggests the need for projects to more actively raise the awareness of the civil society organizations as to their work.

Prospects and Areas for Investment in CLM

«…What is the main problem now? Funding - that's clear. But the lack of coordination of research and effort – that is the problem. Community's voices are out of sync with each other. Solution? Perhaps a certain council on CLM, which would combine all the data obtained as a result of the efforts of various organizations implementing CLM, coordinate them and issue "nicely presented" results..."

A country consultation participant in Kazakhstan

«…Digital tools are what our key learning should be about. Otherwise, we risk losing contact with our audience, the younger generation..."

A country consultation participant in Kyrgyzstan

In discussing the CLM development prospects in the countries, both in interviews and in country consultations, the following priorities were identified for CLM efforts and development in the countries.

The participants noted that community-led service monitoring built around the **entire treatment cascade** can identify not only treatment and diagnostic challenges, but also other problems, such as stigma, discrimination and gender inequality as barriers to accessing health services. Thus, it makes sense to build the CLM funding and development activities around the treatment cascade, while leaving room for a broader interpretation of the results.

Besides, more than 42% of the respondents noted the importance of using certain digital tools of CLM, although they were not always able to specifically identify them. When discussing digitalization, many respondents logically switched to discussing data security. More than half of the respondents emphasized in one way or another that CLM often involves collecting very sensitive, personal information on people's health and experiences. Consequently, in this context, confidentiality and consent of people are essential for ensuring efficient CLM work and creating a safe space.

Respondents' experience with participation in CLM projects has shown that breach of confidentiality and loss of the sense of security are common reasons why people avoid using health services. Thus, respondents emphasized that the goal of CLM as a public health initiative and area should be carefully balanced with the individual's right to privacy and confidentiality. To ensure that, investment in this area of work is necessary.

The respondents also identified as the key issues and segments for further investment areas that may be conventionally grouped into the following categories:

Problem area	**Investment segment**	**% of responses**

Lack of skilled personnel for CLM implementation	Staff training	82%
Lack of awareness-raising and training materials on what CLM is	Training materials in Russian and/or national languages	73%
Lack and wear of material and technical resources	Technical facilities	63%
Lack of digitalization and data security specialists	Ensuring digitization of services, and expenses for data processing and security	42%
Lack of tools and platforms for official presentation of data, lack of their scientific "weight"	Institutionalization of data collection tools to gain their national acceptance	36%

Table 1

Annex 1. Questionnaire for Interviews with Country Experts

	NAME OF ORGANIZATION:
No.	**Question**
1	Have you ever encountered the concept of community-led monitoring (hereinafter referred to as CLM)? If yes, in what context?
2	How do you understand this definition, what do you think CLM is?
3	Do you know any examples of such initiatives implemented anywhere in the world, Central Asia or Eastern Europe? Please describe everything you know.
	What problem areas in the field of healthcare can be improved by using CLM approaches?
4	Are there any initiatives that in your opinion belong to CLM and that your organization is implementing? Please tell us about them.
5	Do you know any initiatives or projects at the country level that, in your opinion, can be classified as CLM? Who is implementing them? Names of projects or outcome documents (if you know).
6	In which areas of work are CLM projects known to you being implemented, how do you assess them (effectiveness, duration, potential), including your own projects (fill in the assessment table).
7	What funding sources do you know for CLM initiatives in your country? Public, private sector, international organizations and donors? Please be as specific as possible.
8	Do you know any examples when the state, donors, etc. support the statutory activities of an organization, and the organization proactively implements CLM, among other things, using such resources? Please give examples.
9	How are the monitoring system and the obtained results applied in practice? 2 or 3 examples of how this changed the situation.
10	How do organizations dealing with CLM communicate with the government and present data? (CCM, membership in working groups, etc.)
11	What is lacking to make the community-led monitoring approach more widely applicable? Besides finance, what other system changes are needed?
12	What are the key steps for the CLM system to work effectively in the country?
13	Which organizations can and should implement CLM programs in the country?

Annex 2.

Legend. Green – more than 2/3 of the respondents answered in the affirmative. Yellow – more than 1/3 of the respondents answered in the affirmative. Red – less than 1/3 answered in the affirmative.

Area of CLM	**Are any projects being implemented in the country? (yes/no)**	**Sources of funding**	**Do the initiatives being implemented in the country meet the basic principles of CLM?**	**Overall quality of implementation (on a scale from 1 to 10, where 10 is the highest rating)**	**What area has the most serious problems?**	**What do you think are the most applicable ways to overcome these problems?**
Routes of HIV transmission (awareness raising among young people and the general population)		N\a	N\a	N/a	Not funded	Elaborating priorities and mechanisms of funding. Ensuring continuous funding. Holding focus groups on proposals and practices for access to information among young people
HIV prevention		GFATM EHRA UNDP USAID		8	Focuses on action, addressing specific situations and accountability. Not fully independent	The number must be assessed with the group on a regular basis, as the form of work and composition change. Continuous funding. Staff advanced training
HIV testing		GFATM UNDP EHRA		7	Focuses on action, addressing specific situations and accountability. Not fully independent	Continuous funding. Discussion with donors on establishing independent evaluation mechanisms outside of projects.
HIV treatment		GFATM UNDP		7	Insufficient skills of the staff, including in	

		ITPC EECA			specific issues of treatment. Small scope of programs. Irregularity of collection. Non-acceptance of data by government agencies. Patients' self-stigma, and complexity of data collection	Continuous funding. Advanced training of staff in treatment and co-infections. Transfer of the best practices from other countries of the region in treatment monitoring and funding.
Adherence to treatment, drug resistance, monitoring and management of side effects		GFATM UNDP		7		
Co-infections (hepatitis, tuberculosis)		GFATM CRG		5		
Human rights and the right to health (including stigma and discrimination)		USAID GFATM		5	Irregularity of programs. Lack of coordination between NPOs. Lack of funding	Developing modules on self-stigma and self-acceptance
Funding HIV programs		GFATM		6	Ensuring the indicator is often considered more important than the quality of services	Elaborating priorities and mechanisms of funding. Ensuring continuous funding. Discussion with donors on establishing independent evaluation mechanisms outside of projects.
Specific needs of key groups		N\a	N\a	N/a	Not funded	Elaborating priorities and mechanisms of funding. Ensuring continuous funding.