



# THE ASSESSMENT OF THE ABILITY OF COMMUNITY-LED ORGANIZATIONS IN UKRAINE TO MONITOR THE QUALITY AND COMPLETENESS OF HIV-ASSOCIATED SERVICE PACKAGES

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The Assessment of the Ability of Community-Led Organizations in Ukraine to Monitor the Quality and Completeness of HIV-Associated Service Packages  
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Opinions expressed in this report are those of the authors, which may differ from those of other stakeholders, and do not anyhow reflect position of the donors of this study.

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# LIST OF ABBREVIATIONS

|                |   |
|----------------|---|
| <b>AIDS</b>    | Acquired Immunodeficiency Syndrome                            |
| <b>CLM</b>     | Community-Led Monitoring                                      |
| <b>CLO</b>     | Community-Led Organization                                    |
| <b>HIV</b>     | Human Immunodeficiency Virus                                  |
| <b>IDI</b>     | In-Depth Interview  |
| <b>LGBTQI+</b> | Lesbian, Gay, Bisexual, Trans, Queer, Intersex communities    |
| <b>M&amp;E</b> | Monitoring and Evaluation                                     |
| <b>NTHC</b>    | National Council on TB and HIV/AIDS                           |
| <b>PHC</b>     | Center for Public Health of the Ministry of Health of Ukraine |
| <b>PLWH</b>    | People Living With HIV  |
| <b>SW</b>      | Sex Workers   |
| <b>TB</b>      | Tuberculosis  |

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# I. INTRODUCTION

“Community-led monitoring (CLM) is an accountability mechanism for HIV responses at different levels, led and implemented by local community-led organizations of people living with HIV, networks of key populations, other affected groups, or other community entities”.<sup>1</sup>

CLM applies structured process to systematically and routinely collect and analyze qualitative and quantitative data on various aspects, including HIV service delivery, access, quality and human rights.

CLM data builds evidence on what works well, what is not working and what needs to be improved, with suggestions for targeted action to improve health outcomes. The purpose of CLM is to serve as a surveillance and accountability community mechanism (i.e., a watchdog function) for health services.

Communities affected by HIV in Ukraine have been providing feedback on the quality of health service provision for quite a while. However, CLM practice and mechanisms fragmentarily cover the essential issues on service quality, access, and barriers. Frequently CLM mechanisms lack adequate frequency of data collection, as well as lack follow-up advocacy on emerging barriers in HIV programmes. Furthermore, gathering, collecting, and using CLM data, has not necessarily been systematic. Consequently, decision-makers often lack data and analysis from the perspective of service users, and interventions may not accurately respond to community priorities and experiences. This imbalance of knowledge and power in service design and provision particularly penalizes minority and stigmatized groups.

Thus, “the assessment of the ability of community-led organizations in Ukraine to monitor the quality and completeness of HIV-associated service packages”, was conducted.

The purpose of this assessment is to identify the existing practice, gaps in implementation and level of institutional capabilities of local community-led organizations.

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<sup>1</sup> Establishing community-led monitoring of HIV services UNAIDS, 2021  
[https://www.unaids.org/sites/default/files/media\\_asset/establishing-community-led-monitoring-hiv-services\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf)

## II. EXECUTIVE SUMMARY

The assessment was conducted applying analytical case-study design and used a framework-based mix-method approach and consisted of in-depth interviews with key informants representing leading community-led organizations and review of literature around existing practices of CLM in Ukraine.

This report describes key preliminary findings across institutional capabilities of community-led organizations to implement quality and structured CLM, across major blocks of implementation approaches and techniques, financing, human resources, and follow-up advocacy.

The study findings suggest that there are gaps in institutional capacities and abilities of community-led organizations in Ukraine, to implement CLM, and significant efforts directed to institutional strengthening, technical support and capacity building are required.

Further study concludes that there is lack of systematic support to CLM on national level, including lack of recognition of CLM generated data, and existence of accountability mechanisms to CLM.

Thus, with purpose to ensure improved quality of HIV-associated service packages in line with ground level needs of affected communities, we recommend concentrating efforts on strategic national support to CLM, including its systematic integration in national surveillance and monitoring and evaluation (M&E) systems, as well as systematic approach to capacity building and community system strengthening.

# III. ASSESSMENT METHODOLOGY

## 3.1. Study Aims and Objectives

The overall aim of the study was to better understand the capacities, level of implementation and systematic institutionalization of Community Led Monitoring among community-led organizations in Ukraine.

Specific objectives:

To achieve the overall study aim, the following key research questions (objectives) were set:

1. What is the level of understanding and approach to implementation of CLM among community-led organizations (CLOs) in Ukraine?
2. How CLM is institutionalized within the community-led organizations and what institutional systems exist to implement quality, structured and systematic CLM?

In answering these questions, it is critical to understand how CLM is currently implemented and what are technical capacities of CLOs to implement it, if CLM is an integral part of institutional systems and processes of organizations, and if it's implemented regularly and systematically, if CLM is standardized and if there are sample data collection and analytical frameworks, if CLM is translated into advocacy and how this advocacy is implemented.


## 3.2. Study Design

The study applied an analytical case-study design and used a framework-based mix-method approach to answer the research questions above. The analytical framework is built around key components of institutionalization of CLM within organizations and includes the following:

- a) CLM implementation practice, instruments, and methodologies;
- b) existence of dedicated, sufficient and sustainable budget for CLM implementation;
- c) approach to development of Human Resources engaged in CLM, including peer-monitors;
- d) practice of translating CLM generated data into evidence;
- e) follow-up advocacy process to apply CLM data in decision-making.

## 3.3. Methodology

The framework application required a mixed-method approach using in-depth interviews and desk review.



The desk review of documents helped the research team to understand what experience is generated within the country, and what is the level of systematic support to CLM within the national strategies and programmes.

In-depth Interviews (IDI) were carried out with the representatives of local community-led organizations, who were able to share information and knowledge on existing practices of CLM implementation, as well as share information on their own organizational capacities related to CLM.

IDIs have been conducted, with community-led organizations representing the following communities: - People living with HIV (PLWH), Women living with HIV, People who use drugs (PUD), LGBTQI+ community, Prisoners, Sex workers (SW), People affected by TB. In total 8 IDIs have been conducted with 8 persons, including 4 women.

All community-led organizations covered with interviews are engaged in delivery of low-threshold HIV prevention services, as well as are engaged in advocacy processes. Moreover, all organizations are members of the National Council on TB and HIV/AIDS (NTHC). These factors have been main principles in selecting the respondents for interviews.

The study used Framework-Based Coding to simplify and standardize the analysis of the collected data. The conceptual framework used in the study protocol formed the bases for the coding. Each QUOTE was characterized with five qualifiers that reflected practice and approach to implementation of CLM by CLOs, including Implementation practice and methods, Budget, Human resources, Evidence production, and Advocacy.



## IV. RESULTS

This section provides analytical description of the results of the assessment. Presented results are analyzed in line with analytical framework of the assessment methodology and structured through five main blocks of the framework: 1. CLM implementation practice 2. Budget 3. Human Resources 4. Evidence Generation 5. Advocacy.

### 4.1. CLM implementation practice

Community-led organizations in Ukraine hold considerable experience in implementation of community-led monitoring, including sound experience in collecting data on the availability and quality of HIV and TB services. Moreover, community-led organizations apply diverse approaches to CLM, including on-site data collection and even digital tools. Most of organizations are involved in collecting data on community needs and services for community members, as well as monitoring of both health care services and human rights violations. Further, community-led organizations conduct various assessments and studies in regards to the needs of community for health services and human right, however the efficiency of using the collected data, most likely, is not yet high enough.

Even though there is quite significant experience, study revealed that community-led organizations in Ukraine still lack capacity and systematic approach to CLM implementation. It should be noted that there are significant disparities between selected community-led organizations. While some organizations (two) apply a more structured and systematic approach to data collection, including digital tools to collect community feedback, the others lack robust data and information collection frameworks and techniques.

It should be noted that existence of specific instruments/tools for data collection are crucial in systematization and structurization of CLM interventions. Digital technologies are of an added value having even higher impact on routine and structured gathering of information and better engagement of communities to provide their feedback, report challenges and gaps in service, or human rights violations. This statement is justified by a fact that successful practice of CLM exists in those organizations who apply standardized tools and digital instruments for CLM. Some of successful cases of CLM practice implemented by community-led organizations include:

### **Example 1. FreeLife**

FreeLife is an application that collects information about all services provided by the state and the public sector to convicts and persons released from prisons in a single electronic space.

FreeLife aims to:

- to improve the access of convicts and those released from prisons to information and resocialization services (medical, social, legal, educational)
- to establish an effective system of interaction between subjects of social patronage of those released on the territory of Ukraine.
- ensure timely response to problems/barriers and monitor their resolution.

FreeLife allows to monitor the quality of services for the treatment of HIV, tuberculosis, viral hepatitis and drug addiction in prisons and probation bodies, to monitor and promptly respond to cases of violations of the rights of released and convicted persons.

It's important to highlight that FreeLife is an instrument that has been fully developed by community.

### **Example 2. Onelmpact**

Onelmpact is a digital platform made up of three tools that work together to provide a comprehensive community empowerment, community engagement and community-led monitoring solution that puts people at the heart of the TB response. Onelmpact CLM aims to empower people affected by TB with information, ways to engage and report TB challenges, as they relate to:

- Barriers to TB health services;
- Human rights violations;
- TB stigma;
- Barriers to TB support services.

Importance and success of Onelmpact can be described through the fact that it not only collects community feedback on challenges in accessing TB care, however, promotes two way communication with patients and acts as a tool to inform and educate patients on their rights, available services, as well as connects patients' community.

It is important to mention, that introduction and implementation of both FreeLife and OneImpact in Ukraine has been supported by Public Health Center (PHC) within the framework of the Global Fund programme. The partnership of community-led organizations and PHC aimed to support and develop the direction of CLM, create an enabling environment between the communities and the public sector by ensuring communication, mechanisms and inclusion of CLM at the national level.

Furthermore, important achievement of this process is systematization and recognition of CLM, as an instrument to collect strategic information and inform policy and practice. Specifically, both FreeLife and OneImpact have been included as an instruments of national M&E system to monitor barriers in access to care and human rights violations.

Both described cases provide justification to two main points: a) existence of structured, well-developed instruments, and framework for data collection are an essential building blocks of quality CLM at community level; b) Strategic partnership of national authorities with communities, with allocation of sufficient resources, is essential in establishing integrated CLM, recognized as part of the national M&E system.

*"The organization has been implementing the CLM since 2017 in the format of collecting data on existing barriers, and by 2023 this has grown into a national policy of data exchange with the state, which adjusts the flow of data between obtaining data, digitizing and analyzing this data, bringing it into national recommendations for improving legislation and thereby communicating through established channels of communication with government officials to intervene in the system in order to improve the situation at the systemic level through legislation or policy change. The CLM reflects twelve key requests of people; these requests correspond to twelve barriers formed in 2017 with the support of StopTB Partnership, the PHC, and several NGOs that are service providers for people on ART and undergoing treatment for TB. The organization is interested in analyzing these barriers and monitoring changes, as this directly reflects the effectiveness of the CLM, which is implemented through the Oneimpact system. The system has been integrated into the web version and in hospitals with the support of the national program of installing infoboxes, so there is no limit to people who need additional consultations. If a request is for a different profile, it will be redirected to the appropriate constitution, as the fundamental goal is to pay attention to everyone who needs help. Given the scale of the partnership in Ukraine and abroad, the organization's administrative center is responsible for verifying data and referring people for help, so these barriers include medical, social, economic, psychological, legal, material, and mental factors."*

*Olha Klymenko, CO "TV PEOPLE OF UKRAINE".*

However, the study revealed that, despite some successful case examples, most organizations lack structured approach to CLM implementation and require further technical and financial support in strengthening community systems in relation to CLM implementation and follow-up. It can be summarized that collection of the CLM data and information is not organized, organizations have no established strategy on what data they are collecting and when, data collection and overall CLM process doesn't take place on the routine bases and is mostly based on the resources available at the given time.

In addition, the study revealed that community-led organizations do not perform assessment of resources and context prior to planning and implementation of CLM. Thus, they lack structured understanding of the context, analyses of their own strengths and weaknesses, opportunities and potential threats.

As for the CLM implementation approach, the majority of the organizations mostly rely on the feedback generated by beneficiaries of services these organizations provide, while there is limited to no contact with wider community members.

Furthermore, review of the existing literature reveals that there is no common understanding nor standard for CLM implementation in the country. Data that should be generated within the CLM is not standardized, and CLM is not considered to be an instrument to inform decisions and strategies.

## **4.2. Budget**

Study suggests that there are significant gaps in the available dedicated budget to CLM implementation within all organizations. Overall, CLM has a lack of financial support within the national HIV response. Lack of financial support for CLM can be explained through limited overall strategic support to CLM on national level. Based on analyses of key strategic and policy documents, it can be concluded that CLM isn't considered as an essential action and is not sufficiently prioritized within national HIV/AIDS strategic plan, the Global Fund programme, nor within the national M&E system of HIV response. This leads to lack of allocated resources to CLM on all levels. While limited resources directly affect organizations' ability to implement systematic and quality CLM.

Moreover, organizations do not necessarily apply the budget planning process for CLM implementation. As mentioned, they frequently have no defined strategy, work plan and respectively budget for activities related to CLM.

Lack of budget concerns both CLM implementation interventions, as well as resources available to invest into development of institutional systems of CLM and capacity building of human resources.

*"The organization does not have a special separate budget for CLM, but negotiations are underway to allocate separate funding for the following years"*

*Oleh Dymaretskyi,  
All-Ukrainian Association of People with Drug Dependence (VOLNA)*

*"The organization does not implement CLM on a regular basis and does not have a special budget and work plan for CLM. However, the need for monitoring is indicated in the operational and strategic plans, but is not budgeted. Currently, a platform for collecting information is being approved."*

*Olena Stryzhak, CO "Positive Women"*

### **4.3. Human Resources**

Information collected within the study reveals that there are important gaps in relation to human resources engaged into the CLM implementation.

Firstly, it should be noted that in most cases there are no dedicated staff engaged into the CLM implementation, while these obligations are mostly implemented by peers/staff members along with their other duties within the organizations.

Furthermore, no organization has established technical reference for CLM implementation to fairly and structurally identify skills required to implement CLM in practice, collect and analyze data etc.

Moreover, no organization has a human resource development strategy. Capacity building of peers/staff members engaged into CLM is rather chaotic and in its best depends on resources available with some short scale projects. Even these interventions mostly concern a trainings or other short term activities, while strategic approach to development of human capacities engaged in CLM on different levels doesn't exist.

*"There is an analyst of consolidated information at the central office, and there are trained interviewers at the research sites who are instructed during shifts. There is no human resources development strategy for regular development and training of civic monitors."*

*Natalia Isaieva, CO "LEGALAIFE UKRAINE"*

*"Paralegals and a monitoring and evaluation expert are engaged in CLM implementation. There is no human resource development strategy for the regular development and training of community monitors"*

*Tetyana Lebid, All-Ukrainian Association of Drug Addicted Women "VONA"*

It's important to highlight that within the last years there has been increase in resources available within international and regional organizations to provide capacity building of communities in CLM. However, these actions are more of a general nature, include trainings or other capacity strengthening interventions on general issues of CLM. While is lack of resources and targeted actions to provide technical assistance to communities in strengthening sustainable human resource development within their organizations.

#### **4.4. Evidence Generation**

Translating CLM generated data into evidence or presenting data in an analytical and structured manner is essential to further inform decision-making and improved services.

However, the study revealed that there is lack of experience and capacity among community-led organizations to properly analyze the generated data, present evidence and develop evidence-based products for further advocacy (e.g. policy briefs, evidence summaries, case study reports, etc.)

Organizations mostly use CLM generated data within verbal and informal communication processes, or present data in unstructured way. This approach limits probability to influence the decision-making process or rely on CLM data and information while planning strategies and programmes.

*"The monitoring is purely proactive, discussions take place at working meetings."*

*Yuriy Lazarevych, CO "100 PERCENT LIFE. RIVNEE"*

Moreover, significant challenge is the quality of collected data within CLM. This challenge is related to the fragmented nature of data collection, lack of standardized approach to what data is collected and why, and poor monitoring protocols.

*"The organization does not have standardized tools for collecting and analyzing data"*

*Andriy Chernyshov, NGO ALLIANCE GLOBAL*

*"The organization has just started implementing CLM, but the right to health has been monitored on a regular basis since 2018, when the organization started its activities. The services are implemented through the databases obtained through the FREE LIFE application"*

*Oleksiy Zahrebelnyi, FREE ZONE.*

However, it should be noted that the scale of this problem is mostly related to lack of standardization of CLM, and not recognition of CLM data as a strategic information to inform, monitor or evaluate progress of national HIV response.

#### **4.5. Advocacy**

Study revealed that most of the community-led organizations are actively engaged in advocacy and participate in key decision-making and coordination processes on different levels. There is good understanding of the key national processes and advocacy is implemented on a regular basis as a core of organizational actions.

However, there is limited experience of affecting the decisions based on and in-line with CLM generated data.

Firstly, it is related to gaps in evidence production as described in the previous section. Community-led organizations also lack an approach to presenting solutions based on the information and data they collect and analyze. They mostly present the raw data, without structured recommendations and solutions for action.

Secondly, advocacy is limited as there are no formal accountability mechanisms that integrate CLM. Specifically national surveillance and monitoring systems do not include CLM as a routine instrument for collection of strategic information.

*"There is no further advocacy at the moment."*

*Natalia Isayeva, CO "Legalife Ukraine"*

The study also revealed that there is lack of coordination between community groups, to join forces and form coalitions, to advocate for the service-related needs of affected communities.

## V. KEY FINDINGS

Based on the generated information, analyzed data and preliminary results described above, it can be concluded that the ability of community-led organizations in Ukraine to monitor the quality and completeness of HIV-associated service packages is limited.

Firstly, it is related to lack of organizational capacities and limited integration of CLM as a core function within the organizational structure. This corresponds to capacity gaps across all major blocks of CLM planning and implementation, including lack of data generation and analytical frameworks and instruments, lack of dedicated financial resources, lack of capacity building and human resource development strategies of personnel engaged into CLM.

Secondly, the reason for limited ability is related to lack of structured support and system in place to translate CLM generated data into evidence, propose solutions for service improvement and respectively follow-up advocacy. This in its own, limits organizations' abilities to influence decision-making processes and ensure that CLM generated data is applied for strategic decisions and programme planning.

In addition to the limited capabilities of the community-led organizations, we can conclude that CLM lacks strategic support on the national level. This is justified by the fact that CLM is not standardized, recognized as an instrument for generating strategic information and is not part of the national surveillance and monitoring and evaluation framework. Furthermore, on national level CLM lacks financial and technical support.



## VI. RECOMMENDATIONS

Results and findings of the assessment described above, inform set of recommendations that we propose to improve CLM implementation and capabilities of community-led organizations to monitor the quality and completeness of HIV-related service packages.

### Recommendations for Community-Led Organizations

Ensure proper assessment of context and respective planning, prior to implementation of CLM.

- Conduct a deliberative process that may include a formal or informal situational analysis of organizational strengths, weaknesses, opportunities and threats in relation to CLM.
- Identify and describe CLM-related funds and other resources available or likely to become available.
- Develop a CLM implementation work plan on an annual basis.

Develop a robust data and information framework and data collection tools.

- Define standardized indicators and data required to monitor and evaluate the quality and completeness of HIV-related service packages.
- Elaborate standardized data collection tools and integrate them within the routine CLM process.

Build a standardized process of CLM implementation as a core function of the organizational actions and structure. This process to consider the following steps in implementation of CLM:

- Identifying needs
- Collecting information
- Analyzing and interpreting collected information and suggesting solutions
- Disseminating information
- Implementing advocacy
- Monitoring the results and achievements

Define and allocate dedicated budget for CLM implementation.

- Allocate sufficient budget for CLM implementation process.
- Allocate sufficient budget for development of institutional systems and human resources related to CLM.

Ensure capacity building and development of human resources engaged into CLM on different levels.

Establish a follow-up mechanism of advocacy.

- Define standardized terms of reference for CLM implementation.
- Define dedicated staff for CLM (data collection, data analyses, etc.)
- Ensure continuous capacity development of human resources, including peer monitors.
- Ensure the analyses of the CLM generated data and translate it into evidence.
- Produce CLM reports, case studies, evidence briefs, position papers, etc. as an instruments for communicating CLM results to the public, decision-makers and other stakeholders.
- Where possible form a coalitions with other community-led organizations to join forces to promote CLM, CLM results, and influence decisions.

### **Policy Recommendations for National Decision-Making Bodies**

National level authorities and decision-making bodies responsible for national HIV response should ensure the following:

- Recognize CLM as an instrument to generate strategic information as part of the national surveillance and monitoring and evaluation systems.
- Provide sufficient financing for community-led organizations to implement CLM on a routine basis.
- Allocate resources required for technical assistance and capacity building to strengthen community-led organizations in CLM implementation.
- Ensure that communities and their constituents are meaningfully engaged into all decision-making processes and there are formal accountability mechanisms to CLM generated data on quality of and access to HIV services.

## Recommendations for Donors

Donors and development partners working in the HIV, TB and cross-cutting fields should strengthen their strategic support to community system strengthening, including strengthening CLM capacities of community-led organizations. In particular the focus should be placed on:

- Provide strategic and financial support to strengthening institutional systems of community-led organizations.
- Allocate financial resources and provide technical assistance in capacity building to strengthen community-led organizations in CLM implementation.
- Place efforts towards standardization of CLM on national level in line with guidelines and technical documents of international organizations.
- Influence national authorities and hold them accountable for recognizing CLM as a strategic instrument for monitoring and evaluation and foster community informed decisions.

# ANNEXES

## Annex I. List of Key Informants

| N° | Name                | Organization  |
|----|---------------------|---|
| 1  | Oleksii Zahrebelnyi | CO "Free Zone" (FREE ZONE)  |
| 2  | Oleg Dymaretskyi    | CO "All-Ukrainian Association of People with Drug Addiction (VOLNA) |
| 3  | Olha Klymenko       | CO "TV PEOPLE OF UKRAINE"   |
| 4  | Andrii Chernyshov   | NGO "ALLIANCE. GLOBAL"  |
| 5  | Natalia Isayeva     | CO "LEGAL LIFE-UKRAINE"   |
| 6  | Tetiana Lebid       | All-Ukrainian Association of Drug Addicted Women "VONA"             |
| 7  | Olena Stryzhak      | CO "Positive Women"   |
| 8  | Yuriy Lazarevych    | CO "100 PERCENT LIFE. RIVNE"  |

## **Annex 2. List of Reviewed Literature**

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