



THE ASSESSMENT OF LEVEL OF SYSTEMATIC INTEGRATION AND RECOGNITION OF COMMUNITY-LED MONITORING OF HIV SERVICES IN UKRAINE

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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

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Treatment
CBO	Community Based Organization
CCM	Country Coordinating Mechanism
CLM	Community-Led Monitoring
CSO	Civil Society Organization
CSS	Community System Strengthening
HIV	Human Immunodeficiency Virus
IDI	In-Depth Interview
MoH	Ministry of Health
MSM	Men who have Sex with Men
PHC	Public Health Center
RC for M&E	Regional Centers for Monitoring and Evaluation
SDG	Sustainable Development Goals
TB	Tuberculosis
UCDC	Ukrainian Centre for Socially Dangerous Disease Control

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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”.¹

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

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.

An important consideration contributing to quality and structured CLM is recognition of CLM by national system and its integration across major functions. To implement quality CLM of an integrated nature,

the following system functions should be addressed: The national HIV response should integrate CLM through a comprehensive policy and strategic framework. CLM should be prioritized within national strategies and action plans, recognizing its role as an essential tool for monitoring service quality, access levels, human rights violations, and generating strategic information. Further, adequate and sustainable financial resources must be allocated directly to communities for CLM implementation. The national legal and regulatory framework have to recognize the importance of CLM in informed decision making, acknowledging communities as providers and implementers of CLM and setting clear standards for its definition, implementation, and utilization of results. Moreover, national accountability mechanisms should integrate CLM, and routine surveillance and monitoring systems incorporate CLM as a standard instrument for data collection. Overall, this comprehensive approach emphasizes the value of CLM in achieving effective HIV responses and promoting community empowerment and ownership.

¹ 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

National HIV response, including policy, system and practice are expected to consider and recognize that communities affected by HIV have unique and valuable knowledge and insights regarding their specific needs, challenges, and strengths. Furthermore, meaningful community engagement and participation can lead to more responsive and effective HIV services. And lastly, empowering communities to monitor and advocate for their rights and needs fosters ownership, accountability, and sustainability in HIV programs.

While Ukraine has been facing numerous challenges in its efforts to combat HIV/AIDS, these challenges have been exacerbated by the full-scale Russian invasion and ongoing war. Before the war, Ukraine already had one of the highest HIV prevalence rates in Europe. However, the war has further complicated the situation by disrupting healthcare infrastructure, displacing populations, and undermining prevention and treatment efforts. In particular, the war has resulted in the destruction or closure of healthcare facilities in conflict-affected areas, limiting access to HIV testing, counseling, and treatment services. Displaced populations often struggle to find appropriate healthcare,

leading to interruptions in antiretroviral treatment (ART) and increasing the risk of treatment failure and drug resistance. The conflict has hampered the provision of prevention services. Disrupted supply chains and the displacement of key personnel have limited the availability of these services, leading to an increased risk of new HIV infections. Further, displacement resulting from the war has created a vulnerable population at a higher risk of HIV transmission. Displaced individuals face increased stigma, reduced access to healthcare, and limited resources, making them more susceptible to engaging in high-risk behaviors. Moreover, the breakdown of social support networks can negatively impact their ability to adhere to treatment regimens. Moreover, the conflict has disrupted the collection and reporting of HIV data, hindering the ability to track the epidemic accurately. Lack of access to conflict-affected areas and the displacement of healthcare personnel have resulted in gaps in data, making it difficult to assess the true extent of the problem and allocate resources effectively. Considering the mentioned context, and negative consequences of war, the role of CLM gains even more importance. CLM helps identify gaps in HIV prevention, testing, treatment, and

care services resulting from the conflict. Communities on the ground can provide valuable insights into specific challenges faced by affected populations, such as limited access to healthcare facilities, disruptions in supply chains, or barriers to service utilization. During times of war, human rights violations can occur, leading to stigma, discrimination, and limited access to services for vulnerable populations. Community-led monitoring enables the early detection of such violations, enabling immediate interventions to protect the rights of people living with HIV and key populations. Further, CLM can facilitate the establishment of strong linkages between healthcare providers, community-based organizations, and affected populations. This collaboration improves referrals, ensures comprehensive care, and enhances the continuum of HIV ser-

vices, even in conflict-affected areas.

Communities affected by HIV in Ukraine have extensive experience in CLM implementation and providing feedback on the quality of health service provision for quite a while. Further Ukraine also has an experience of collaboration between state institutions and communities on the CLM, within the Global Fund supported programmes. However, CLM still lacks systematic approach and requires further integration as an essential part of national systems, in order to contribute to ensuring accurate response to community priorities, needs and experiences. Thus, considering the mentioned context “the assessment of level of systematic integration and recognition of community-led monitoring of HIV services in Ukraine” has been conducted.

II. ASSESSMENT METHODOLOGY

2.1. Study Aim and Objectives

The overall aim of the study was to better understand the level of implementation and systematic integration of Community-Led

Monitoring in Ukraine and the enablers and disablers to this.

Specific Objectives:

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

1. Systematic Integration - What political, financing, and systematic factors influence institutionalization and integration of CLM?
2. What are critical enablers and disablers, respectively facilitating or hindering implementation and systematic integration of CLM?

In answering these questions, it is critical to understand what the key considerations for implementation of the quality CLM are,

that is an integral part of the national HIV response systems, and what internal and external factors influence this integration.

2.2. 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 figure. This framework provides an overview of the elements or themes that we see as important to quality of CLM, as well as questions that are important to have information on with respect to each of the elements. Answers to these questions and themes are particularly important to inform cross-component analysis.

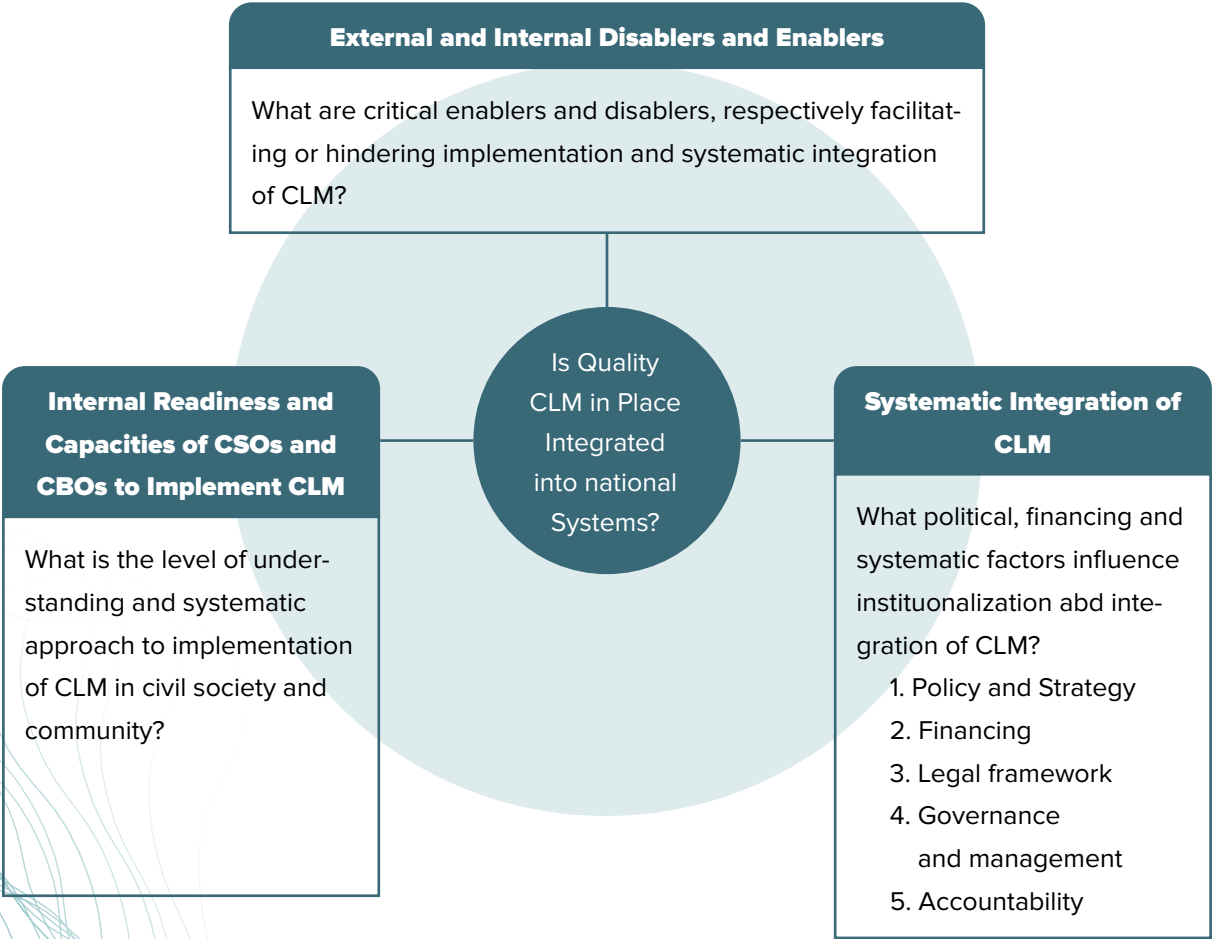
Analytical framework includes a simple schematic (Figure 1) that helps illustrate our understanding of the factors affecting quality of CLM, as well as guiding questions linked to each of the elements of

The analytical framework is build around two core components (in line with the research questions of the study):

- 1. Systematic integration of CLM into national HIV response, that includes:
 - a) Policy and Strategic Framework
 - b) Financing of CLM
 - c) Legal Framework
 - d) Governance and Decision Making
 - e) Monitoring, evaluation and strategic information

- 2. External and internal disablers and enablers
 - a) What are critical enablers facilitating systematic integration of the CLM?
 - b) What are the critical disablers hindering systematic integration of the CLM?

Figure 1. Analytical Framework



2.3. 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 the current context around CLM, level of systematic support, and integration into national policies, strategies and programmes.

In-depth Interviews (IDI) were carried out with the representatives of Public Health

Center (PHC) of Ministry of Health of Ukraine, who were able to provide more practical information on CLM implementation and integration.

The study used Framework-Based Coding to simplify and standardize the analysis of the collected data. The analytical framework used in the study protocol formed the bases for the coding.

III. RESULTS

This section provides analytical description of the results of the assessment. The presented results are analyzed in line with analytical framework of the assessment methodology and structured through five main blocks of the framework:

3.1. Policy and Strategy

With purpose to implement quality CLM and ensure that community needs are reflected in national programmes, national policies in the field of HIV have to integrate obligations and political support for CLM on national level, through prioritizing it with national strategies and action plans. CLM should be recognized by national policy and strategy as an essential instrument of monitoring of quality of services, level of access to services, human rights violations, etc.

Ukraine adopted a public health approach to countering epidemics and in 2019 the Cabinet of Ministers of Ukraine approved a unified HIV/TB/Hepatitis strategy up to 2030 to align to sustainable development goals (SDG) 3.3. goal. The strategy focuses on prevention programs targeting key populations while expanding access to

1. Policy and Strategy 2. Financing
3. Legal Framework 4. Governance and Management 5. a) Monitoring, evaluation and strategic information. Further critical enablers and disablers are described across each block/section.

treatment. It has three strategic goals for HIV, TB, and Hepatitis.

Based on the analyses of the strategy, as well as the Global Fund programme, it can be summarized that the important role of civil society and community in national HIV and TB responses is widely recognized.

Apart from the engagement of civil society and communities into service delivery, their role and engagement in monitoring is also acknowledged and supported. Both strategy and especially the Global Fund programme focuses on “community-based monitoring” of access to HIV services, human rights violations, as well as promotes community system strengthening (CSS) and meaningful engagement of communities into decision-making.

CSS component is focused on capacity building of key population led Civil Society Organizations (CSOs) and Community Based Organizations (CBOs). This includes institutional support and development of communities at the national and regional level. Community strengthening interventions propose a comprehensive approach to improve and increase capacity for advocacy, monitoring, communication, and mobilization both at the national and regional levels.

However, assessment revealed, that despite existence of support to community-led monitoring, as well as commitments to support both CLM and community-led advocacy efforts, national policies and strategies in HIV field lack focus on systematization and integration of CLM. In particular, CLM is not formally recognized as an instrument to inform strategic decision making, not as an integral part of the national monitoring and evaluation system of HIV response. Furthermore, there is no common understanding nor standardized approach to implementation of

community-led monitoring in the country. The HIV monitoring and evaluation system in Ukraine plays a crucial role in tracking the prevalence, impact, and response to HIV/AIDS within the country. The system involves a comprehensive framework for monitoring and evaluating various aspects of the epidemic, including surveillance, prevention programs, treatment, and care services.

HIV monitoring and evaluation system in Ukraine is regulated by decree of cabinet of ministers “On the Unified System of Monitoring and Evaluation of the Efficiency of Measures Aimed at Preventing the Spread of HIV Epidemic” and orders of Ministry of Health (MoH) “On Approval of the National Plan of Monitoring and Evaluation of the National Programme on HIV Prevention, Treatment, Care and Support for HIV-positive Persons and AIDS patients”. As of mid-2023 the latest monitoring and evaluation action plan is under development and is expected to be approved by the end of the year.

Both literature review and key informant interviews informed the report about the key features of the monitoring and evaluation system, those include:

- **Surveillance:** Ukraine has a well-established HIV surveillance system that collects, analyzes, and disseminates data on HIV/AIDS. It includes routine monitoring of new HIV infections, HIV prevalence among key populations (such as people who inject drugs, sex workers, and men who have sex with men), and other relevant indicators. This surveillance helps identify trends, target interventions, and measure the impact of prevention and treatment efforts.
- **Prevention Programs:** The monitoring and evaluation system assesses the effectiveness of HIV prevention programs in Ukraine. It tracks the coverage and quality of prevention services, such as condom distribution, harm reduction interventions (needle and syringe programs). This information allows policymakers and stakeholders to refine and optimize prevention strategies to reduce new infections.
- **Treatment and Care:** The system also monitors the availability, accessibility, and quality of HIV treatment and care services. It tracks indicators like the number of people living with HIV on antiretroviral therapy (ART), viral load suppression rates, and retention in care. This data helps evaluate the effectiveness of the treatment cascade, identify gaps in service provision, and guide efforts to improve HIV care and support.
- **Impact Evaluation:** The monitoring and evaluation system conducts regular impact assessments to measure the overall impact of HIV programs in Ukraine. It assesses key outcomes, such as reductions in new HIV infections, AIDS-related deaths. These evaluations provide valuable insights into the success of interventions and inform evidence-based decision-making for resource allocation and program improvement.
- **Data Management and Reporting:** The system ensures proper data management, analysis, and reporting. It utilizes standardized tools and protocols for data collection and establishes mechanisms for data quality assurance.

3.2. Financing

The cornerstone of effective CLM implementation is political support, reflected in institutionalization, and most importantly financial support. Sufficient and sustainable financial resources have to be allocated for implementation of CLM and channeled directly to communities for its implementation.

Key financing priorities within national HIV response are focused at significant support to service decentralization, improved access to health services, quality models of care, health care financing mechanisms and building public health strategies. Integration of TB and HIV services is ensured at several levels. Available resources are strategically allocated across interventions, geographies and population groups to maximize impact of respective disease programs. Given the funding envelope and the country budget, funding priorities are well-positioned to produce highest impact. Furthermore, analyses revealed that there are financial resources allocated for community system strengthening and investments available for capacity building, as well as elaboration and implementation of CLM modalities. Introduction and implementation of 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, the 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 instrument of the national M&E system to monitor barriers in access to care and human rights violations.

It should be noted that national HIV response, provides sufficient funding for national monitoring and evaluation system and action plan, including financing of both, routine monitoring as per key indicators of the M&E action plan, as well as separate surveys and assessments directed to assess the effectiveness. However, there is lack of financial resources available to CLM, including institutionalize CLM. Lack of strategic support to CLM institutionalization and integration leads to lack of allocated resources available.

Specific constraints in relation to sustainable financing of community-led monitoring (CLM) in Ukraine include the following challenges. Firstly, there are fragmented funding streams, with various sources supporting CLM, such as the Global Fund program and other donors. However, these different funding sources have different priorities, making it difficult to align resources effectively. Efforts should focus on securing "core funding" for CLM, institutionalizing it, and improving coordination among key stakeholders.

Secondly, CLM initiatives are not adequately integrated into national or local health budgets in Ukraine and rely heavily on donor funding. This lack of integration can lead to insufficient financial allocations for monitoring activities and a lack of legitimacy for CLM results, which hampers sustainability and effectiveness.

Thirdly, Ukraine has a well-established system of state funding and procurement of services from civil society organizations and community-led organizations. However, funding communities through the state budget for monitoring other state-supported services raises concerns about conflict of interest, impartiality, and integrity. Therefore, the funding system for CLM and related advocacy activities needs careful consideration and elaboration.

Fourthly, due to competing priorities and limited resources, health systems often prioritize other essential interventions, such as treatment programs or prevention services, over community-led monitoring initiatives. With the ongoing war in Ukraine, the government's focus is on emerging issues, further limiting their ability to invest in HIV programs. Consequently, the probability of sustainable financing for CLM through the state budget is very limited. Integrating CLM into the national monitoring and evaluation system becomes crucial to increase the likelihood of funding as part of the national system.

Lastly, the role and value of community-led monitoring are not fully recognized or coordinated within health systems. This lack of recognition and coordination leads to limited investment and support for CLM initiatives.

Addressing these challenges from a health systems perspective requires strengthening health financing mechanisms, improving coordination and integration of community-led monitoring initiatives, investing in capacity building for financial management, and advocating for policy changes that prioritize sustainable funding for HIV monitoring at the community level.

3.3. Legal Framework

Community-led monitoring plays a vital role in ensuring effective HIV response measures. Further it empowers communities affected by HIV to actively participate in decision-making processes, hold institutions accountable, and advocate for their rights. To ensure the success of community-led monitoring initiatives, a strong legal framework is essential. In this section we explore the legal aspects and frameworks supporting community-led monitoring, highlighting key elements and gaps in Ukraine.

The legal framework over community-led monitoring should foster transparency, accountability and responsiveness. In other words, it should recognize CLM as integral part of generating strategic information and national system of monitoring and evaluation, where decision-making and strategy development is accountable and responsive to data generated by community groups.

Analyses of the literature reveal that there are major gaps in CLM legal framework.

First and foremost, there is lack of CLM adapted right to information, there are no specific legal provisions requiring healthcare providers to disclose relevant information to HIV prevention, treatment, and care services. Thus, organizations engaged into community-led monitoring

are forced to base analyses of monitoring efforts and analytical work only on community feedback. Thus, mechanisms for timely and accurate reporting, data collection, and dissemination should be established.

Secondly, legal framework doesn't recognize CLM as an instrument to inform strategic decisions. In this regard, the CLM should be standardized, including clear definition of what data should be collected and data collection mechanisms.

Further, stigma and discrimination, as well as criminalization of key population groups in Ukraine, might limit their ability to participate in community-led monitoring activities. Thus, legal framework on national level should promote equal access to healthcare services and protect the rights of individuals, ensuring they are not hindered from participating in CLM.

Lastly, limited information has been generated within the desk review on data protection and confidentiality. Legal provisions safeguarding the privacy, confidentiality, and security of individual health information are crucial. Community-led monitoring initiatives rely on accurate and reliable data, and the legal framework should ensure the protection of personal health information, informed consent, and strict adherence to ethical standards.

3.4. Governance and Management

Coordination and decision making, ensuring the meaningful engagement of communities and accountability to CLM generated data is of utmost importance.

The National TB and HIV/AIDS Council (CCM) is a key coordination and decision-making body in HIV in Ukraine. CCM oversees the overall implementation of the Global Fund grants and ensures proper coordination between different sectors as well as different programs implemented by other external partners. CCM monitors the HIV response progress to ensure that the activities are carried out according to the work plan and indicators of programmatic and financial performance are accomplished. It makes the key financial and programmatic decisions and has the responsibility to address the main problems and challenges. To effectively perform its supervisory duties CCM has established the CCM Oversight Commission with respective rights and responsibilities. The Oversight Commission keeps this mechanism to inform CCM on the overall Project implementation progress as well as to report on the on-site supervision and spot check. The CCM and the MOH carry out the role of coordination with other programs and development initiatives. The CCM ensures practical co-

ordination and collaboration with all local partners involved. The representatives of women's organizations, key populations and people living with the diseases are members of the CCM.

Most of CSOs and CBOs are represented in the CCM and are highly active in advocacy, influencing policy changes, promoting decriminalization of sex-work, eliminating the legal vacuum of single-sex couples living as families and to create the proper political and legal conditions for ensuring the rights of men who have sex with men (MSM) to the highest attainable level of health, on the decriminalization of drug use, sexual and reproductive health rights for women living with HIV and decreasing gender-based violence, documenting human rights violations, conducting community-based monitoring, reducing stigma and discrimination. These networks also have increased focus on self-organizing and capacity building.

Further, the governance and structure of national HIV monitoring and evaluation system has been analyzed. M&E activities are coordinated and implemented by The Ukrainian Centre for Monitoring and Evaluation of Program Activities to Counter HIV / AIDS and Tuberculosis (M&E Centre).

The M&E center was established by order of the Ministry of Healthcare of 09.04.2009, N° 236 for the purpose of monitoring and evaluation of program activities to counter HIV and TB at the national and regional levels, dissemination of information on the spread of HIV / TB epidemic.

The M&E Centre is a separate structural unit of State Institution 'Ukrainian Centre for Socially Dangerous Disease Control' (UCDC) of the Ministry of Healthcare of Ukraine. The M&E Centre provides for the establishment of a unified system of monitoring and evaluation of actions to counter HIV/AIDS and tuberculosis. Its tasks also include implementation of comprehensive systematic monitoring of the process and results of actions pertaining to countering HIV / AIDS and tuberculosis, determining their effectiveness; ensuring reliability, objectivity and integrity of information, its pertinence to the tasks of national programs; ensuring the access to databases on M&E. One of the main objectives of the Centre is the M&E coordination and support of the 26 regional centers for monitoring and evaluation (RC for M&E) operating in each region of Ukraine.

Operating through HIV-specific/dedicated M&E centers in Ukraine, is quite

unique and advanced practice, that creates opportunities for strengthened monitoring and evaluation both on central, as well as tertiary levels. However, improved coordination efforts, including close collaboration with community organizations, are required to further advance the process and integrate CLM.

It can be concluded that, even though community-led organizations actively participate in country coordinating mechanisms, and respective decision-making processes, there are certain concerns in relation to sustainability. These concerns are mostly related to the fact these mechanisms are donor driven. Thus, laws should facilitate meaningful participation of affected communities in decision-making processes related to HIV policies, programs, and resource allocation. Mechanisms such as participatory governance structures, community representation, and consultation processes should be legally established to ensure community voices are heard and integrated into decision-making. Further, despite existence of well-structured monitoring and evaluation coordinating structure, improved coordination with communities is essential.

3.5. Monitoring and Evaluation

One of the major gaps in ensuring institutionalization of CLM is lack of its integration into national monitoring and evaluation system. Integrating community-led monitoring into national HIV monitoring and evaluation systems enhances the accuracy, relevance, and responsiveness of these systems.

Integration of CLM into national M&E system has the following strengths: a) Community-led monitoring promotes transparency and accountability by involving affected communities in monitoring the implementation of HIV programs and services. It ensures that the voices and perspectives of key populations and people living with HIV are heard, fostering greater accountability among service providers and policymakers. b) Further CLM brings grassroots knowledge and insights into the monitoring and evaluation

process. By integrating community-generated data, national HIV monitoring and evaluation systems can capture real-time information on service accessibility, quality, and effectiveness, leading to more accurate and context-specific data. c) Community-led monitoring provides timely feedback on program strengths, gaps, and challenges. This information helps shape targeted interventions and policy adjustments, ensuring that HIV programs meet the specific needs of communities and key populations. d) Integrating community-led monitoring fosters greater community engagement, ownership, and trust. When communities actively participate in monitoring and evaluation, they become more invested in the HIV response, leading to increased community support, resource mobilization, and program sustainability.

Analyses revealed that CLM is not an integral part of monitoring and evaluation system in Ukraine. Despite that certain interventions are considered to be integrated and plan on unified electronical system are in place, core challenges in integration include:

- **Capacity Building:** Building the capacity of community members and organizations to effectively monitor and evaluate HIV programs is crucial. Training and support should be provided to ensure communities have the necessary skills and knowledge to collect, analyse, and utilize data for monitoring and evaluation purposes. While capacity building interventions are in place, focus on institutional strengthening of organizations in CLM implementation is not prioritized.
- **Data Integration and Standardization:** In Ukraine CLM generated data as well as data collection methods are not standardized. Integrating community-generated data into national monitoring and evaluation systems requires careful attention to data integration, standardization, and quality assurance processes. Harmonizing community-led monitoring data with existing data systems is essential to ensure comparability and usefulness at the national level.

Further, in order to ensure integration of CLM into monitoring and evaluation system the following strategies should be applied: a) Policy and Legislative Support: National HIV monitoring and evaluation frameworks should explicitly acknowledge and support community-led monitoring. Incorporating provisions for community engagement, data sharing, and participation in policy and decision-making processes strengthens the legal and policy foundations for integration. b) Data Integration and Standardization: Develop guidelines and protocols for integrating community-generated data into national monitoring and evaluation systems. Ensure compatibility with existing data systems, establish data quality assurance

mechanisms, and facilitate data sharing between community-based organizations and national stakeholders. c) Collaboration and Partnerships: Foster partnerships between community-based organizations, civil society groups, government agencies, and other stakeholders involved in the HIV response. Collaborative efforts facilitate knowledge exchange, resource mobilization, and joint decision-making processes. d) Recognition and Support for Community Expertise: Recognize and value the expertise of community members and organizations in monitoring and evaluation. Provide resources, technical support, and platforms for community-led monitoring initiatives.

IV. FINDINGS

Based on the generated information and analyzed data, it can be concluded that despite the existence of significant efforts targeting community system strengthening and community-led monitoring, Ukraine faces major gaps in recognition of CLM as a strategic instrument for monitoring

and generating data to inform decisions, as well as its integration across national monitoring and evaluation systems.

This statement is justified through findings across need to improve core systematic functions across CLM.

Firstly, national policy and strategy in the field of HIV lacks political support to CLM as an integral part of national monitoring and evaluation system, or tool to inform strategic decisions. A significant gap is the absence of clear and comprehensive policy frameworks specifically addressing community-led monitoring of HIV. National HIV strategies and policies do not explicitly incorporate community-led monitoring or provide guidelines for its implementation. This lack of clarity

and guidance results in inconsistent approaches and limited institutional support for community-led monitoring initiatives. In this regard, efforts should be made on the development of comprehensive policy frameworks that explicitly recognize and support community-led monitoring of HIV. These frameworks should provide guidelines for implementation, institutional support, and coordination mechanisms among stakeholders.

Key findings in regard to policy and strategy, include:

- **Integration of Community-Led Monitoring CLM:** The findings indicate the importance of integrating CLM into national policies and strategies in the field of HIV. This integration is necessary to ensure that community needs are reflected in national programs and to monitor the quality of services, level of access to services, and human rights violations.
- **Role of Civil Society and Community Engagement:** The findings highlight the recognized and supported role of civil society and communities in national HIV and TB responses. Their engagement in service delivery and monitoring efforts is acknowledged and encouraged.

- **Community-Based Monitoring and Community System Strengthening (CSS):** The findings emphasize the focus on community-based monitoring of access to HIV services, human rights violations, and the promotion of CSS. The CSS component aims to build the capacity of key population-led organizations, promoting advocacy, monitoring, communication, and mobilization at the national and regional levels.
- **Gaps in Systematization and Integration of CLM:** The findings reveal that despite existing support for community-led monitoring and advocacy efforts, national policies and strategies in the HIV field lack a systematic and integrated approach to CLM. CLM is not formally recognized as an instrument for strategic decision-making, nor is it an integral part of the national monitoring and evaluation system of the HIV response. Furthermore, there is no common understanding or standardized approach to implementing community-led monitoring in the country.
- **HIV Monitoring and Evaluation System:** The findings highlight the crucial role of the HIV monitoring and evaluation system in tracking the prevalence, impact, and response to HIV/AIDS within Ukraine. The system encompasses surveillance, prevention programs, treatment and care services, impact evaluation, and data management.
- **Potential of CLM in Strengthening the Monitoring and Evaluation System:** The findings suggest that community-led monitoring can strengthen the data collection, analysis, and decision-making processes within the HIV program. It has the potential to enhance the effectiveness of HIV prevention, treatment, and care efforts, aligning them with the needs of the final beneficiaries.
- **Limited Institutionalization of CLM:** The findings conclude that while community system strengthening, including community-led monitoring, is somewhat supported within existing programs, the institutionalization of CLM is not considered an essential action. It lacks sufficient prioritization within national HIV/AIDS strategic plans, the Global Fund program, and the national monitoring and evaluation system of the HIV response in Ukraine.

Secondly, insufficient funding is a significant barrier to the sustainability and scale-up of community-led monitoring initiatives. Community-based organizations often struggle to secure long-term funding for their monitoring activities, hindering their ability to effectively carry

out monitoring and evaluation processes. Governments, donors, and international organizations should prioritize funding opportunities that support community-based organizations and ensure sustained financial support for their monitoring efforts.

Key findings in regard to financing, include:

- **Political and Financial Support:** Effective implementation of CLM requires political support, institutionalization, and sufficient financial resources. Financial support must be allocated and directed directly to communities to ensure the sustainability of CLM.
- **Funding Priorities:** Within the national HIV response, funding priorities focus on service decentralization, improved access to health services, quality models of care, health care financing mechanisms, and public health strategies. Integration of TB and HIV services is also ensured at various levels.
- **Resources for CLM:** The analysis reveals that financial resources are allocated for community system strengthening, capacity building, and the elaboration and implementation of CLM modalities. Initiatives like FreeLife and OneImpact have been supported by the Public Health Center (PHC) through the Global Fund program, contributing to the systematization and recognition of CLM as an instrument for collecting strategic information and informing policy and practice.
- **Insufficient Funding for CLM:** While the national HIV response provides sufficient funding for the national monitoring and evaluation system, there is a lack of financial resources available for CLM, including its institutionalization. The lack of strategic support and integration of CLM results in insufficient allocated resources.
- **Constraints in Sustainable Financing:** Constraints in sustainable financing for CLM in Ukraine include fragmented funding streams, limited integration into health budgets, weak health financing mechanisms, resource allocation prioritization, and lack of recognition and coordination within health systems.

- **Fragmented Funding Streams:** Fragmented funding sources result in different priorities for CLM, making it challenging to align resources effectively. Efforts should focus on securing core funding for CLM, institutionalization, and improved coordination among stakeholders.
- **Limited Integration into Health Budgets:** CLM initiatives in Ukraine are mostly supported by donor funding and are not adequately integrated into national or local health budgets. This lack of integration can lead to insufficient financial allocations and a lack of legitimacy for CLM results.
- **Weak Health Financing Mechanisms:** While Ukraine has a well-established system of state funding and procurement of services, funding communities through the state budget for monitoring state-supported services needs to be addressed to ensure impartiality and integrity.
- **Resource Allocation Prioritization:** CLM initiatives face competition with other essential health interventions for limited resources. The ongoing war in Ukraine has further limited the government's ability to invest in HIV programs, making sustainable financing for CLM through the state budget challenging. Integration of CLM into the national monitoring and evaluation system is crucial to increase the likelihood of its funding.
- **Lack of Recognition and Coordination:** The role and value of community-led monitoring are not fully recognized or coordinated within health systems, resulting in limited investment and support.

Thirdly, it can be concluded that a strong legal framework is essential for the success of community-led monitoring initiatives. It should foster transparency, accountability, and responsiveness, recognizing CLM as an integral part of generating strategic information and the national system of monitoring

and evaluation. The analyses revealed major gaps in the CLM legal framework in Ukraine, related to recognition of CLM, required regulatory environment for its integration, ensuring confidentiality and ethics in data management, as well as issues related to external factors of stigma and discrimination.

Key findings in regard to the legal framework, include:

- **Lack of Right to Information:** There is a lack of specific legal provisions requiring healthcare providers to disclose relevant information to HIV prevention, treatment, and care services. This limits community-led monitoring organizations to rely solely on community feedback, necessitating the establishment of mechanisms for timely and accurate reporting, data collection, and dissemination.
- **CLM not Recognized for Strategic Decisions:** The legal framework does not recognize CLM as an instrument to inform strategic decisions. Standardization is needed, including a clear definition of the data to be collected and mechanisms for data collection.
- **Stigma, Discrimination, and Criminalization:** Stigma, discrimination, and the criminalization of key population groups in Ukraine can limit their ability to participate in community-led monitoring activities. The national legal framework should promote equal access to healthcare services and protect the rights of individuals, ensuring their unhindered participation in CLM.
- **Data Protection and Confidentiality:** Limited information is available on data protection and confidentiality within the legal framework. Legal provisions safeguarding the privacy, confidentiality, and security of individual health information are crucial. The legal framework should ensure the protection of personal health information, informed consent, and adherence to ethical standards.

Addressing these gaps in the legal framework requires incorporating the right to information, recognizing CLM for strategic decision-making, promoting equal access to healthcare services, and strength-

ening data protection and confidentiality measures. A robust legal framework will provide the necessary support and protection for community-led monitoring initiatives in Ukraine.

Fourthly, the study concludes that despite the active participation of community-led organizations in country coordinating mechanisms and decision-making processes, there are concerns about sustainability as these mechanisms are often donor-driven. Laws should facilitate meaningful participation of affected communities in decision-making processes

related to HIV policies, programs, and resource allocation. Establishing participatory governance structures, community representation, and consultation processes can ensure that community voices are heard and integrated into decision-making. Additionally, improved coordination between the monitoring and evaluation structure and communities is essential.

Key findings in regard to the governance and management, include:

- **Integration of CLM within the Monitoring and Evaluation System:** Although Ukraine has a well-structured monitoring and evaluation system for HIV, there is a need for better integration and coordination with community-led monitoring initiatives. While HIV-specific M&E centers exist, there is still a lack of comprehensive integration of CLM within the national monitoring and evaluation framework. Strengthening the coordination and collaboration between the M&E system and community organizations is crucial to maximize the potential of CLM in generating accurate data and informing decision-making processes.
- **Lack of Institutionalization:** The absence of formal recognition and institutionalization of CLM within national HIV policies and strategies is a significant challenge. CLM is not considered an essential action and lacks prioritization within the national HIV/AIDS strategic plan, the Global Fund program, and the national monitoring and evaluation system. This lack of institutional support and recognition undermines the sustainability and effectiveness of community-led monitoring efforts.
- **Donor Dependency and Sustainability:** One of the main challenges is the heavy reliance on donor funding, which raises concerns about the long-term sustainability of community-led monitoring initiatives. The current mechanisms for coordination and decision-making are predominantly donor-driven, which may hinder the continuity and stability of CLM efforts once external funding diminishes. There is a need to develop sustainable financing mechanisms that prioritize CLM and ensure its integration within national HIV policies and programs.

- **Coordination and Community Engagement:** While community-led organizations actively participate in country coordinating mechanisms and decision-making processes, there are concerns regarding the sustainability and meaningful engagement of communities. The existing mechanisms are largely donor-driven and may not adequately incorporate the voices and perspectives of affected communities. Improved coordination efforts, including closer collaboration with community organizations, are necessary to ensure that community-led monitoring is effectively integrated into the overall HIV response.

Addressing these critical problems and challenges requires sustained efforts to establish sustainable financing mechanisms, strengthen the legal framework to protect the rights of individuals and ensure the effectiveness of CLM, improve coordination and meaningful engage-

ment of communities, and institutionalize CLM within the national HIV response. By addressing these challenges, Ukraine can enhance the impact and sustainability of community-led monitoring initiatives, ultimately improving the overall response to HIV/AIDS.

Fifthly, the study identified limited integration and utilization of community-generated data within national monitoring and evaluation systems, as one of the key gaps. Community-led monitoring data is often not fully integrated or utilized in the decision-making processes of national HIV programs, leading to missed opportunities for improving program effectiveness. Thus, the focus should be placed

on establishing mechanisms for integrating community-generated data into national monitoring and evaluation systems, including development of protocols and guidelines for data sharing and utilization, ensuring that community-led monitoring data is valued, analyzed, and incorporated into programmatic decision-making processes.

Key findings in regard to the monitoring and evaluation, include:

- **Lack of Integration:** The major gap in institutionalizing Community-Led Monitoring (CLM) is the lack of its integration into the national HIV monitoring and evaluation system in Ukraine. This omission hinders the accuracy, relevance, and responsiveness of the overall monitoring and evaluation framework.
- **Data Integration and Standardization:** CLM-generated data and data collection methods in Ukraine are not standardized. Integrating community-generated data into the national monitoring and evaluation systems requires attention to data integration, standardization, and quality assurance processes. Harmonizing community-led monitoring data with existing data systems is essential for comparability and usefulness at the national level.
- **Capacity Building:** Building the capacity of community members and organizations to effectively monitor and evaluate HIV programs is crucial. However, in Ukraine, the focus on institutional strengthening of organizations in CLM implementation is not prioritized. There is a need to prioritize capacity building interventions and provide training and support to communities, ensuring they have the necessary skills and knowledge for data collection, analysis, and utilization.

Lastly, community-led monitoring relies on the expertise and knowledge of affected communities. However, there is often a lack of recognition and valuing of community expertise in monitoring and evaluation processes. Community members' inputs are not adequately considered or integrated into decision-making, limiting the impact of community-led monitoring. Thus, meaningful inclusion of community

representatives in decision-making processes and program development should be ensured. The expertise of community members and organizations should be recognized and valued by actively seeking their inputs, engaging in participatory processes, and incorporating their perspectives in monitoring and evaluation activities.

V. 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.

Policy Recommendations for National Decision-Making Bodies

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

- **Develop comprehensive policy frameworks:** Create clear and comprehensive policy frameworks that explicitly recognize and support community-led monitoring (CLM) of HIV. These frameworks should provide guidelines for implementation, institutional support, and coordination mechanisms among stakeholders.
- **Integrate CLM into national policies and strategies:** Ensure that CLM is integrated into national policies and strategies in the field of HIV. This integration will help reflect community needs in national programs, monitor service quality and access, and address human rights violations.
- **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.**
- **Strengthen the legal framework:** Establish a strong legal framework that fosters transparency, accountability, and responsiveness. This framework should recognize CLM as an integral part of generating strategic information and the national system of monitoring and evaluation.

- Establish participatory governance structures: Facilitate meaningful participation of affected communities in decision-making processes related to HIV policies, programs, and resource allocation. Establish participatory governance structures, community representation, and consultation processes to ensure that community voices are heard and integrated into decision-making. 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:

- Prioritize funding for CLM: Allocate sufficient financial resources to support community-based organizations and their monitoring efforts. Prioritize funding opportunities that sustainably support community-led monitoring initiatives.
- Allocate financial resources and provide technical assistance in capacity building to strengthen community-led organizations in CLM implementation.
- Provide strategic and financial support to strengthen institutional systems of community-led organizations.
- Support sustainable financing mechanisms: Work with the government and other stakeholders to develop sustainable financing mechanisms for CLM. Address issues such as fragmented funding streams, limited integration into health budgets, and weak health financing mechanisms.
- Place efforts towards standardization of CLM on national level in line with guidelines and technical documents of international organizations.
- Advocate for institutionalization of CLM: Encourage the institutionalization of CLM within national HIV policies and strategies. Advocate for its recognition as an essential action and ensure its integration into the national monitoring and evaluation system. Influence national authorities and hold them accountable for recognizing CLM as a strategic instrument for monitoring and evaluation and foster community informed decisions.

Recommendations for Communities

Communities, and community-led organizations should place their efforts on the following:

- **Strengthen community-led monitoring capacity:** Focus on capacity building for community members and organizations to effectively monitor and evaluate HIV programs. Prioritize training and support to communities, equipping them with the necessary skills and knowledge for data collection, analysis, and utilization.
- **Enhance data collection and analysis skills:** Communities should invest in building their capacity to collect, analyze, and interpret data related to HIV. This includes training community members on data collection methodologies, data management, and data analysis techniques. Developing these skills will empower communities to generate high-quality data that can inform decision-making processes.
- **Advocate for community representation:** Communities should advocate for meaningful inclusion and representation in decision-making processes related to HIV policies, programs, and resource allocation. This can be achieved by actively participating in national and local HIV coordinating mechanisms, engaging in dialogue with policymakers, and ensuring that community perspectives and priorities are heard and integrated into decision-making processes.
- **Engage in decision-making processes:** Actively participate in decision-making processes related to HIV policies, programs, and resource allocation. Advocate for meaningful inclusion of community representatives, ensuring that their expertise and perspectives are considered and integrated into monitoring and evaluation activities.
- **Strengthen community networks:** Communities should establish and strengthen networks among community-led organizations and affected populations. These networks can serve as platforms for sharing knowledge, experiences, and best practices in community-led monitoring. By collaborating and learning from each other, communities can amplify their voices and collectively advocate for their rights and needs.

- Foster collaboration and partnerships: Communities should actively seek collaboration and partnerships with other stakeholders, including government agencies, donors, and non-governmental organizations. Building strong partnerships will enhance the visibility and influence of community-led monitoring initiatives, and facilitate access to resources, expertise, and support.
- Promote community mobilization and awareness: Communities should engage in community mobilization activities to raise awareness about the importance of community-led monitoring and its impact on HIV programs and services. This includes conducting outreach activities, organizing community dialogues, and leveraging various communication channels to disseminate information about community-led monitoring initiatives and their outcomes.



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