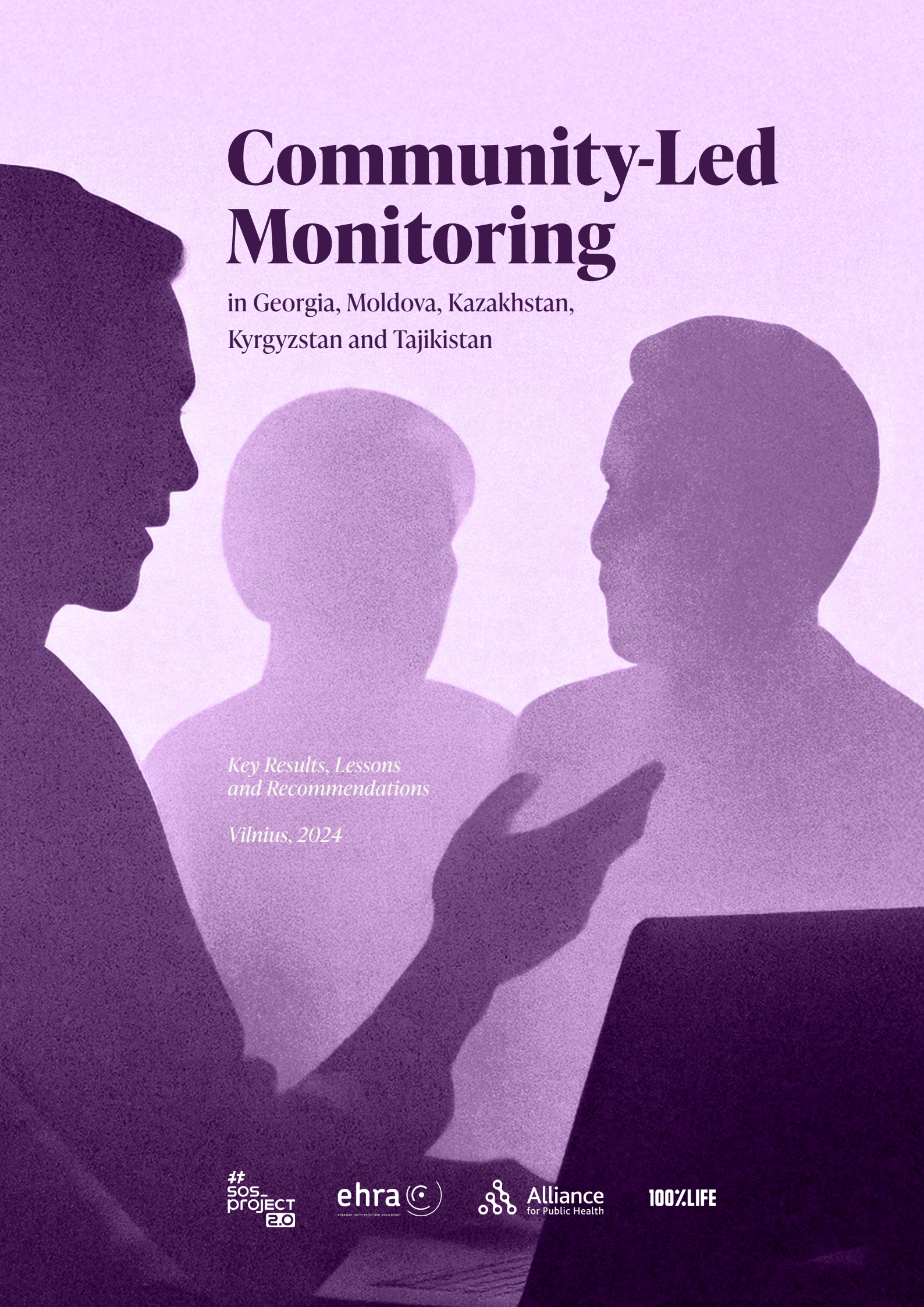




Community-Led Monitoring

in Georgia, Moldova, Kazakhstan,
Kyrgyzstan and Tajikistan

*Key Results, Lessons
and Recommendations*

Vilnius, 2024



Alliance
for Public Health

100%LIFE

This publication was prepared and published by the *Eurasian Harm Reduction Association (EHRA)*, a non-profit, membership-based public organisation that unites and supports more than 300 Central and Eastern European and Central Asian (CEECA) harm reduction activists and organisations to ensure the rights and freedoms, health and well-being of people who use psychoactive substances.

For more information, visit the website: <https://harmreductioneurasia.org/>

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Abbreviations and acronyms

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<i>CCM</i>	Country Coordinating Mechanism
<i>CEECA</i>	Central and Eastern Europe and Central Asia
<i>CLM</i>	Community-led monitoring
<i>EHRA</i>	Eurasian Harm Reduction Association
<i>FGD</i>	focus group discussion
<i>KAP</i>	Key Affected Populations
<i>MoH</i>	Ministry of Health
<i>OAT</i>	opioid agonist therapy
<i>PrEP</i>	pre-contact prophylaxis
<i>RCPN</i>	Republican Centre for Psychiatry and Narcology

Foreword

The *Eurasian Harm Reduction Association (EHRA)* is a non-profit, membership-based public organisation that unites and supports more than 300 Central and Eastern European and Central Asian (CEECA) harm reduction activists and organisations. Its mission is to actively unite and support communities and civil societies to ensure the rights and freedoms, health, and well-being of people who use psychoactive substances in the CEECA region.

The report draws on the three-year project of the EHRA to support community-led monitoring (CLM) initiatives for opioid agonist therapy (OAT) and the findings and results of community groups in *Georgia, Moldova, Kazakhstan, Kyrgyzstan, and Tajikistan*, offering insights into best practices and lessons learnt. It underscores EHRA's efforts to foster collaboration, empower communities, and contribute to evidence-based improvements in OAT services.

The methodology of this report included reviewing reports from this CLM initiative and conducting five interviews with the community focal points for CLM in Kazakhstan, Kyrgyzstan, Moldova, Georgia, and Tajikistan and decision-makers in these countries where possible using qualitative interview guides, which can be found in the Annex to this report.

Part 1 Details the CLM process and underscores the choices of methods, data collection, challenges, and solutions at the country level. It presents the efforts of all community organisations that received funding through a community-oriented open call from EHRA to monitor a topic of their choice. Every funded community initiative focused on OAT, highlighting this treatment's critical importance and lifesaving nature.

Part 2 Presents the findings from CLM initiatives and advocacy based on these data undertaken by community organisations to improve the quality and access to the OAT programmes. It provides an overview of the CLM process, offering insights into its implementation and impact at the country level. The report seeks to compare experiences across five countries, building on the similarities and differences as well as lessons learnt that may be useful for CLM implementers in other countries and from various communities. It emphasises the role of grassroots groups and organisations by people who use drugs and the roles of decision-makers, as well as their collaboration based on the win-win principle in advancing OAT services.

Part 3 Explores EHRA's efforts to support the development of tools and build the capacity of community organisations. It details how EHRA planned for these activities and implemented them, issuing tools and fostering a Community of Practice for CLM. Emphasising skill development, knowledge sharing, and collective learning to advance the implementation of OAT services are looked at as a means of empowering communities and strengthening their ability to engage effectively in CLM and advocacy.

Part 4 Offers actionable recommendations for donors, primarily the Global Fund and governments. These recommendations aim to enhance the effectiveness and sustainability of CLM initiatives.

This report serves as a record of the CLM process, a progress report, and, we hope, a resource to inform future efforts to further enhance community-led monitoring of the effectiveness and quality of OAT programmes.

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Implementing Community-Led Monitoring

Community-led monitoring proved to be a powerful means of highlighting community members' daily challenges. It provides granulated information, particularly around accessing and utilising services designed to meet their needs. CLM helps provide data-driven insights, empowers communities, and facilitates the effective and transparent use of public funds, ensuring services are both impactful and responsive.

Since 2017, EHRA has been dedicated to building capacity on CLM for organisations and initiatives of people who use drugs on various topics, consistently advancing this commitment through its ongoing initiatives. By fostering partnerships between communities, service providers, and decision-makers, EHRA seeks to promote an unbiased understanding of CLM's value and to ensure its results drive impactful solutions for systemic issues. Beyond merely assessing health and social services, CLM in the context of drug use extends its focus to systemic problems such as human rights violations, criminalisation, stigma, and structural violence. It is a powerful tool that reflects the lived realities of people who use drugs while advocating for systemic reforms that enhance their quality of life.

In 2022, EHRA established resources on CLM. It hosted training sessions for the community of people who use drugs, followed by five sub-grants in 2023 for community-led monitoring in Georgia, Moldova, Kazakhstan, Kyrgyzstan, and Tajikistan. These activities belong to the regional project "Sustainability of services for key populations in the region of Eastern Europe and Central Asia" (SoS_project 2.0) within the frames of the initiative by the consortium of organisations led by the Alliance for Public Health in partnership with the CO "100% Life" with financial support from the Global Fund to Fight AIDS, TB, and Malaria. EHRA continued to support follow-up activities in these five countries in 2024, all to facilitate the meaningful change needed for people enrolled on the OAT programme.

EHRA promotes the idea that the community is central to CLM's success. The community must lead every aspect – from deciding what to monitor and which methods to use to interpreting results and driving targeted advocacy. Most importantly, data ownership and resources must rest firmly with the community and serve its interests above all else.

To guide effective implementation, EHRA advocates for the following principles:

- CLM must prioritise the needs and rights of the community.
- The focus should remain on identifying and addressing systemic issues, not individual problems.
- Ethical practices are essential; in other words, service providers or state institutions should not influence monitoring processes or outcomes.
- Importantly, community organisations conducting CLM must remain independent, free from conflicts of interest, and accountable only to the community they represent.
- Results should be openly accessible, fostering transparency and collaboration.

This chapter provides an overview of how community organisations in five countries conducted monitoring of the OAT programme.

Georgia

Georgia has had a 20-year history with OAT programmes (primarily focused on methadone), which have served thousands of patients over the years. Through the efforts of Rubicon, a community-driven organisation, CLM was identified as a powerful mechanism to collect data directly from patients and advocate for reforms that align with international best practices. In 2022, Rubicon's choice to continue monitoring OAT was driven by the pressing need to improve programme implementation and raise patient satisfaction.

For its second CLM initiative, Rubicon embraced the idea of using a unique method, such as patient diaries, after the EHRA webinar on monitoring tools. Patients were encouraged to document their daily lives, challenges, and emotions related to OAT. Ten people, selected for their logistical challenges in accessing OAT centres – such as caregiving responsibilities or disabilities – kept diaries for 1-2 weeks, documenting their daily struggles. There is something profoundly moving about the idea of reading patients' records, where they meticulously documented their daily lives, struggles, and challenges. The approach provided deeply personal, qualitative insights into patients' obstacles when accessing treatment. In addition, it emphasised community empowerment, leveraging the experiences of patients to highlight systemic barriers. These writings convey a deeply emotional narrative: when you read the diaries, it immediately becomes clear what gives pain, what weighs on their minds, and what they endure. The material was genuinely heartfelt and offered a unique glimpse into the inner world of people enrolled on OAT, stakeholders shared afterwards.

While effectively passing the emotional message between structural barriers and lived experience, this method required training participants to reflect deeply and articulate their experiences comprehensively. Rubicon engaged with professional researchers to extract and analyse data for findings and recommendations. The outcome was a rich combination of qualitative and quantitative data that underscored the need for urgent reforms, where results were emotionally compelling and engaging with their target audiences, sensitising and shedding light on the lived realities of people reliant on OAT. Thus, CLM in Georgia helped uncover critical insights into patient daily experiences, offering a foundation for engaging advocacy that complements the evidence collected earlier. Despite this, significant gaps persist, such as inadequate psychosocial support, restricted access to take-home doses, and overly rigid regulations. These findings are discussed in more detail in the following chapter.

Zaza Karchkhadze
Rubicon, Georgia

“We chose patient diaries: patients documented their daily lives, struggles, and challenges, creating deeply moving material that clearly revealed their pain and concerns. These records touch the reader emotionally.”

Moldova

In Moldova, the CLM initiative was born out of the need to address persistent complaints from patients about the OAT programme. These concerns included diluted medications, breaches of confidentiality, and limited access to take-home doses. During the COVID-19 pandemic, the expansion of take-home medication demonstrated tangible benefits, yet post-pandemic policies reverted to daily attendance requirements, complicating patients' ability to work or fulfil their citizen and family obligations. The CLM sought to validate these grievances and advocate for more patient-centred solutions. Led by PULS Communitar, the monitoring efforts focused on evaluating the accessibility, quality, and acceptability of OAT services across the country.

The approach combined surveys and focus group discussions across nine OAT sites in eight locations, including Balti, Orhei, Chisinau (2), Ungheni, Falesti, Comrat, Cahul, and Edinet, engaging with seventy-seven programme participants in nine focus groups without collection of personal data from participants. Focus groups with OAT participants were attached to the location of sites. The number of focus group participants ranged from three to ten people. These methods allowed for in-depth exploration of patient experiences, uncovering challenges that extended beyond the initial assumptions. Partnerships with stakeholders, and importantly with the Republican Narcological Dispensary, enabled site visits, ensured access to facilities for focus groups, and ensured the community groups had necessary premises. This support was granted by a letter from the leadership of the service. Another critical success factor was the inclusion of community members in the research process, ensuring findings reflected lived

Vitali Rabinciuc

PULS COMUNITAR, Moldova

“We chose focus groups because we wanted to see if there were anything we had overlooked in our survey. There were aspects we hadn’t included in the questionnaires, but people [benefiting from OAT] brought up issues we hadn’t even thought to ask about.”

realities. Despite logistical challenges, such as the lack of dedicated resources or offices, PULS Communitar persisted with creative problem-solving and external support, including technical assistance from EHRA.

Initially, there was scepticism about the CLM process, with stakeholders fearing bias by community groups, but trust grew as the monitoring findings aligned with patients' realities and contributed to actionable recommendations. The lack of dedicated government recognition for CLM mechanisms remains a challenge, but the groundwork laid by this project is a step toward institutionalisation. In the following chapter, there is more information on how, in Moldova, the CLM initiative has become a beacon of grassroots action, addressing systemic barriers in the OAT programme and advocating for change.

Kazakhstan

In Kazakhstan, where political pressures and bureaucratic procedures may create cycles and delay progress, CLM has proven critical in amplifying the voices of people who use drugs and mobilising them and their supporters around shared goals. With the support of EHRA, the initiative group of the Forum of People Who Use Drugs, used CLM most recently to document systemic barriers, advocate for reforms, and push for greater accountability in how services are delivered at the Country Coordinating Mechanism (CCM) meetings. Overall, CLM efforts included surveys, interviews, and video testimonials about the OAT programme. By collecting data through interviews and monitoring visits across seven cities – Temirtau, Ust-Kamenogorsk, Uralsk, Kostanay, Rudny, Lisakovsk, and Pavlodar – the initiative highlighted barriers that hinder patients’ access to care and the quality of services they receive. A total of 21 interviews were collected.

Community activists leveraged a combination of interviews and innovative methods, such as video testimonials from OAT participants, to illustrate the programme’s impact on real lives. The use of video formats for interviews stemmed from the value of having relatable voices – peer-to-peer interactions and stories resonated more strongly within the community. The participants selected for the project were already active advocates in the harm reduction space, chosen for their consistent involvement and firsthand experience with OAT. CLM aimed to mobilise individuals within the OAT community to underscore the importance of their own participation in shaping services, which was innovative to the country context, as there were no activists enrolled on OAT opening their faces before this initiative.

Film production and interview data analysis revealed challenges, particularly in communication dynamics during interviews. Some participants initially struggled with articulating their thoughts or managing emotions when recording. For example, one interviewer had to adjust their approach mid-process, recognising the need for clearer communication and self-reflection. Emotional involvement, while inevitable, often complicated the process for both interviewers and participants, especially when discussing personal struggles or societal misconceptions about drug dependence. Another example was the inclusiveness of this initiative for people with disabilities, which made it difficult to decode. A key was the involvement of trained community members in conducting interviews and collecting data. Their own experience fostered trust and enriched the findings with nuanced insights, reinforcing the importance of keeping CLM efforts community driven. The unresolved ethical issue is whether to post those video interviews online: although all participants signed an informed consent form, they are easy to recognise, and the impacts on their daily lives might be negative.

For many, this was their first experience conducting or participating in interviews, and while the initiative was a milestone, it highlighted gaps in practical training. One of the lessons was that remote training sessions were less effective, and when in-person training was later introduced, participants reported needing more time to practice and adapt to the interviewing process. The challenges have been considerable: the unsynchronised start of activities and a slight delay in funding caused some blaming within community groups that created some unwanted negative background, combined with bureaucratic resistance and the need to navigate political sensitivities, which have all

impacted CLM implementation. Despite these hurdles, the initiative succeeded in creating a platform for meaningful dialogue, bringing together patients, healthcare providers, and policymakers to explore solutions.

Overall, CLM has proven essential for patient voices and mobilising the community around shared goals in Kazakhstan. The focus of monitoring included access to take-home doses during hospitalisation, addressing the unique challenges of this key affected population, and ensuring the continuity of OAT in hospitals and detention facilities. These issues are critical, as many individuals with co-occurring health conditions delay or avoid seeking treatment due to inflexible OAT protocols. Additionally, this population can be found in detention. The findings from interviews and video stories highlighted successes in changing the lives of OAT patients and underscored persistent gaps, such as limited access to psychosocial support and inconsistent service delivery across regions.

Valentina Mankiyeva

AMAL Central Asian Women's
Network, Kazakhstan

“If OAT patients themselves start speaking out more and getting more involved, change will happen faster. We’ve seen successful examples in Ukraine and Moldova – everything started with just one patient, and from there, transformations followed. We’d like to hear more voices, not just from the slightly active patients, but also from those who are less engaged. Finding a way to reach to them can bring valuable perspectives. We need to prove and demonstrate that the problems in OAT have persisted for over a decade. Change is essential – it’s no longer possible to ignore.”



Kyrgyzstan

CLM initiative in Kyrgyzstan has served as a practical tool for addressing challenges in OAT provision and shaping effective advocacy. Over two decades, Kyrgyzstan has developed an OAT programme predominantly centred around methadone, creating limited options for patients. The COVID-19 pandemic prompted innovations, such as take-home methadone doses for up to five days, which proved successful in practice but raised legal and regulatory questions. Post-pandemic, the return to stricter controls highlighted gaps in service delivery, including concerns about the availability of alternative treatments like extended-release buprenorphine, which could address safety and misuse issues. Law enforcement continues to target people who inject heroin, even though the drug landscape has evolved substantially in the past decade with a shift from opioids and heroin largely replaced by synthetic substances like salts and mephedrone, while the OAT site work remained unchanged. The mismatch between OAT programme priorities and current realities has strained the capacity of outreach workers, who now face a dramatically increased workload, with some managing up to 250 individuals – a stark contrast to earlier periods, while others argue it might be false. These discrepancies have frustrated, blocked, and stalled the involvement of community organisations, highlighting a broader systemic issue to do with the key population size estimations and donor funding based on them.

Public Fund ‘Peer to Peer’ in Kyrgyzstan, a community group with members who are OAT patients, interviewed OAT patients regarding their satisfaction with the OAT programme and collected examples of countries where OAT medication was dispensed through pharmacies. The project involved a well-coordinated team, with each member responsible for specific

Tatiana Kucheravyh

PEER TO PEER, Kyrgyzstan

“Most surveyors tend to focus on issues like HIV infection and transitioning away from injection drug use. However, for us, as people who use drugs, priorities lie elsewhere: relationships with law enforcement, safety at programme sites, expanding medication options, reducing stigma, and dispelling myths about the programme. The monitoring we conducted was centred around our own needs, concerns, and preferences.”

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tasks. Peer to Peer leveraged its trained community network to ensure high-quality results. A call for participants was published on their website, and they selected individuals with extensive experience in conducting interviews and report writing. From two to three individuals handled data collection; another person input the findings into Excel and created graphs, while someone else compiled and finalised the report.

The initiative included surveys with patients, focusing on issues such as unequal access to OAT services, confidentiality breaches, and challenges in programme efficiency. Across four sites in Bishkek, 38 participants were selected, including thirty men and eight women aged

18–45, with nineteen individuals engaged in either employment or education. The involvement of peer counsellors – individuals with lived experience of drug use – played a key role in gathering meaningful data and fostering trust. One of the challenges was locating clients, as many receive their medications to take home. This required multiple visits to the site and waiting for extended periods to meet with participants.

The goal of advocacy was defined as expanding the range of medicines, dispensing methadone in tablet form, and gaining the ability to receive prescription therapy in pharmacies. Unlike external assessments, CLM allowed

the community to define priorities, conduct monitoring, interpret data, and present findings independently. This autonomy ensured the focus remained on actionable insights rather than fulfilling externally imposed metrics. The CLM efforts were carried out in partnership with the Republican Narcological Centre and other stakeholders. Strong relationships with the centre played a key role in the smooth rolling out of CLM: doctors supported the community by providing meeting rooms and inviting participants. Despite increasing restrictions related to NGO legislation, the team worked collaboratively, selectively addressing recommendations from the report while navigating legal and institutional constraints.

Tajikistan

The CLM in Tajikistan, driven by the initiative group Intihob and supported by NGO SPIN Plus, represents an evolving effort by the community of people who use drugs to enhance OAT programmes and address barriers. The CLM served primarily as a means to train and engage with new activists and as an advocacy tool, reflecting the complexities of translating findings into actionable change in the past years.

The CLM initiative with EHRA support involved engaging with OAT patients through interviews, surveys, and fieldwork. A team of trained activists conducted structured interviews with twenty-five OAT participants across three cities: Dushanbe, Vahdat, and Kulyab. Key informants represented intersecting groups of people who use drugs, sex workers, and people living with HIV, with diverse socioeconomic and health backgrounds.

The interviews revealed systemic challenges such as transportation costs, stigma, limited psychological support, and restrictive OAT

protocols. Despite these findings, community representatives expressed frustration over the limited impact of the monitoring activities, with advocacy efforts stalled due to bureaucratic and legislative hurdles. Many issues, such as take-home medication policies and the absence of OAT access in pre-trial detention centres, were not new and still remain unresolved.

While the initiative achieved partial success in gathering data and raising awareness, activists noted a lack of tangible progress. Activists emphasised the need for robust community engagement and capacity building. The absence of new activists and waning enthusiasm among existing community members were identified as significant challenges. Consequently, an important takeaway is that stakeholders must prioritise empowering community representatives and fostering systemic accountability.

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Pulod Dzhamolov
SPIN PLUS, Tajikistan

“It wasn’t so much of a monitoring as it was an advocacy initiative. We’re working on it now, but this area has always been slow-moving for us. OAT exists as a programme, but certain aspects, like take-home medication, simply aren’t progressing. The participants themselves collected the data and had the questionnaire, but we’ve hit a wall – everyone understands the issue, yet nothing moves forward.”



Key Results of the CLM on the Country Level

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*This chapter presents the findings
and outcomes of the CLM by country.*

Georgia

*Number of people who
inject drugs: 49,700*

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Key findings

Geographical inaccessibility
Daily attendance requirements
Stigma by doctors and other staff
Insufficient psychosocial, social,
and employment support

In 2020–2021 and 2023, *Rubicon* conducted two CLM studies with support from EHRA to identify and document challenges in OAT programmes. The CLM revealed critical insights, some of which were not new for the country’s stakeholders and drug dependence doctors, but now they were grounded on the recent experience of patients, providing a foundation for advocacy.

The key findings focused on the following areas:

- *Geographical inaccessibility:* Patients from remote regions struggle to access OAT services. Daily travel demands considerable time and imposes additional transport costs, exacerbated by the lack of take-home medication options.
- *Daily attendance requirements:* The requirement of daily visits to the institution is very problematic. It makes it challenging to find a job and negatively affects patients’ quality of life. These factors lead to the next problem – the morning queues at programme sites cause patients to arrive late for work, resulting in workplace complications and increased professional stress. Furthermore, overcrowding and long clinic queues disrupt patients’ routines and treatment adherence, interfering with their professional activities and personal lives.
- *Stigmatising attitudes by doctors and other staff:* Many patients faced stigmatising attitudes from staff and substandard service quality, forcing some to self-adjust and reduce their medication doses to decrease the frequency of site visits.
- *Insufficient psychosocial, social, and employment support:* OAT patients reported a lack of psychological support for their mental issues and no social services, with minimal awareness of available NGO resources.

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Rubicon used its CLM findings to advocate for removing barriers that hinder patients’ ability to maintain employment and fulfil personal obligations as citizens.

Thus, the key CLM-based recommendations in Georgia focused on:

- Increasing geographic coverage or establishing additional OAT centres in underserved regions.
- Re-ensuring broad access to take-home doses. The recommendation suggested that stable patients can receive medication for self-administration, reducing the burden of daily visits for patients and doctors and leaving more room for doctor-patient interactions. This will require the revocation of the Ministry of Health (MoH) OAT 2024 regulations and the updating of the clinical protocol and programme management regulations.

- Expanding psychosocial support for OAT patients via integrating psychological and social services to address patients' holistic needs.
- Ensuring patient-centred care by improving staff training to reduce stigma and streamlining documentation processes: a regular measurement of patients' quality of life would assist in correct treatment when needed. It is also necessary to adapt the infrastructure of service centres for people with disabilities.

Pathways to change

Healthcare providers, addiction doctors, and civil society were supportive of the CLM findings, including the MoH, whose initial feedback for Rubicon's recommendations was positive. Moreover, during the COVID-19 pandemic, the Centre for Mental Health and Prevention of Addiction, in consultation with the community of people who use drugs and with support from the Global Fund COVID-19 Grant, proposed to MoH changes to the OAT protocol, inclusive of provisions to receive multiple-day take-home doses and granted greater authority to treating physicians while dissolving the medical commission.

Despite presenting Rubicon's findings on various platforms, including the CCM and the MoH, they remained unaddressed. The CCM, once a reliable platform for collaboration, has not convened in nearly a year, reflecting the broader disengagement of government actors. Efforts to engage with state actors through formal correspondence and meetings yielded little response, reflecting broader systemic resistance to reforms.

In early 2024, a directive from the MoH prohibited take-home doses even for vulnerable groups, inclusive of patients with disabilities or those having active tuberculosis and critically ill patients. It represented a step backwards, undermining adherence and patient well-being. This reversal not only disregarded evidence-based and CLM recommendations but also exacerbated patient hardships, essentially imposing a choice between maintaining employment and adherence to treatment for some of them. A Multi-Stakeholder Dialogue Meeting on Harm Reduction and Drug Policy in Georgia, held in May 2024 and supported by EHRA, brought together the country's stakeholders. Many invited officials did not attend, except for the Centre for Mental Health and Prevention of Addiction. Furthermore, a continuous turnover among officials within key government agencies has hindered communication with civil society, and the leadership, often lacking public health expertise, has deprioritised OAT programmes. Some attribute the decreasing prioritisation of these programmes to the flip

Khatuna Totadze, MD
Centre for Mental Health and
Addiction Prevention, Georgia

"We need to work towards making OAT programmes more humane. It is unrealistic and inhumane to expect someone who has been in an OAT programme for months or years to show up every single day. Excessive bureaucracy forces doctors to focus on paperwork rather than patients. Allowing take-home doses would free up doctors' time in favour of interactions with patients."

side of successes in HIV prevention achieved with Global Fund support, suggesting that the focus now needs to shift toward addressing the growing issue of drug addiction.

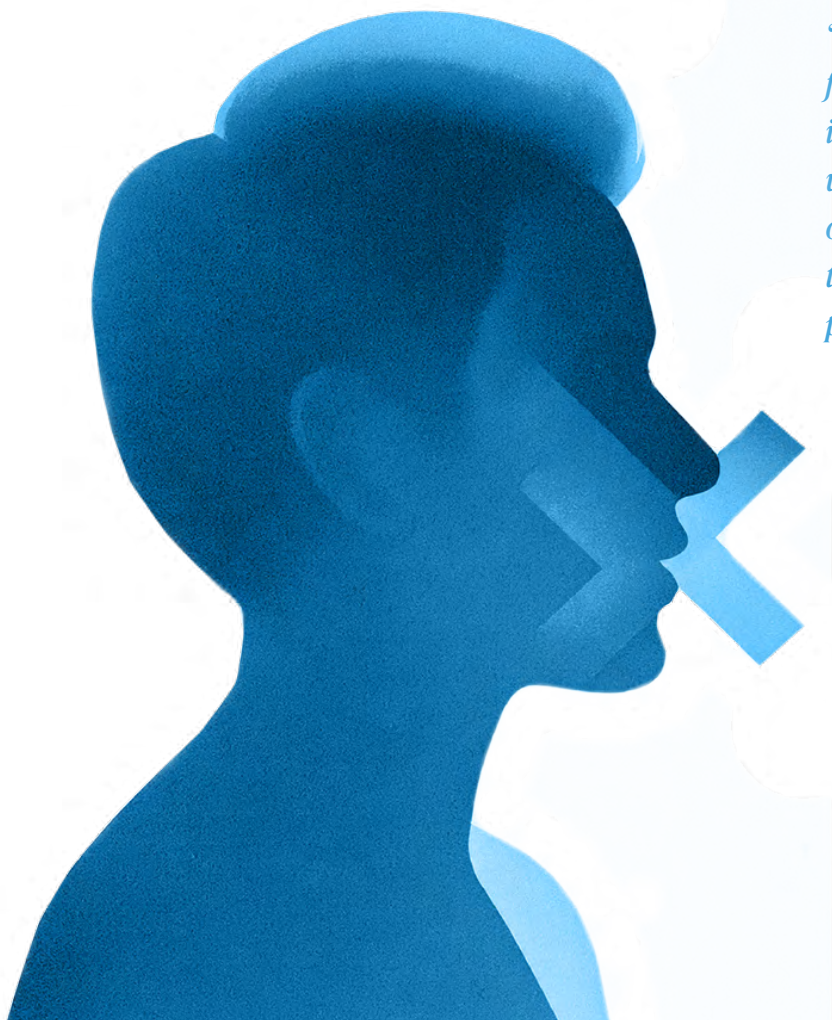
The political environment in Georgia continues to pose more obstacles: restrictive policies, new laws, and a lack of engagement from state institutions limit opportunities for dialogue, while tightened restrictions cancelling take-home doses put pressure on patients.

Thus, with successful data collection and analysis processing in the CLM, political barriers have complicated advocacy in Georgia, and recommendations were not integrated into practices. To better amplify patient voices, the community is expected to increase its presence in public space through meetings, social media engagement, and webinars. Despite setbacks, Rubicon continues to seek new approaches, including regular communication with country stakeholders, international support, and collaboration with global and regional partners like EHRA. These partnerships are crucial for maintaining momentum in advocacy and addressing political and systemic challenges. Moving forward, an international dialogue between the Global Fund actors and government officials in the MoH will be essential.

Zaza Karchkhadze
RUBICON, Georgia

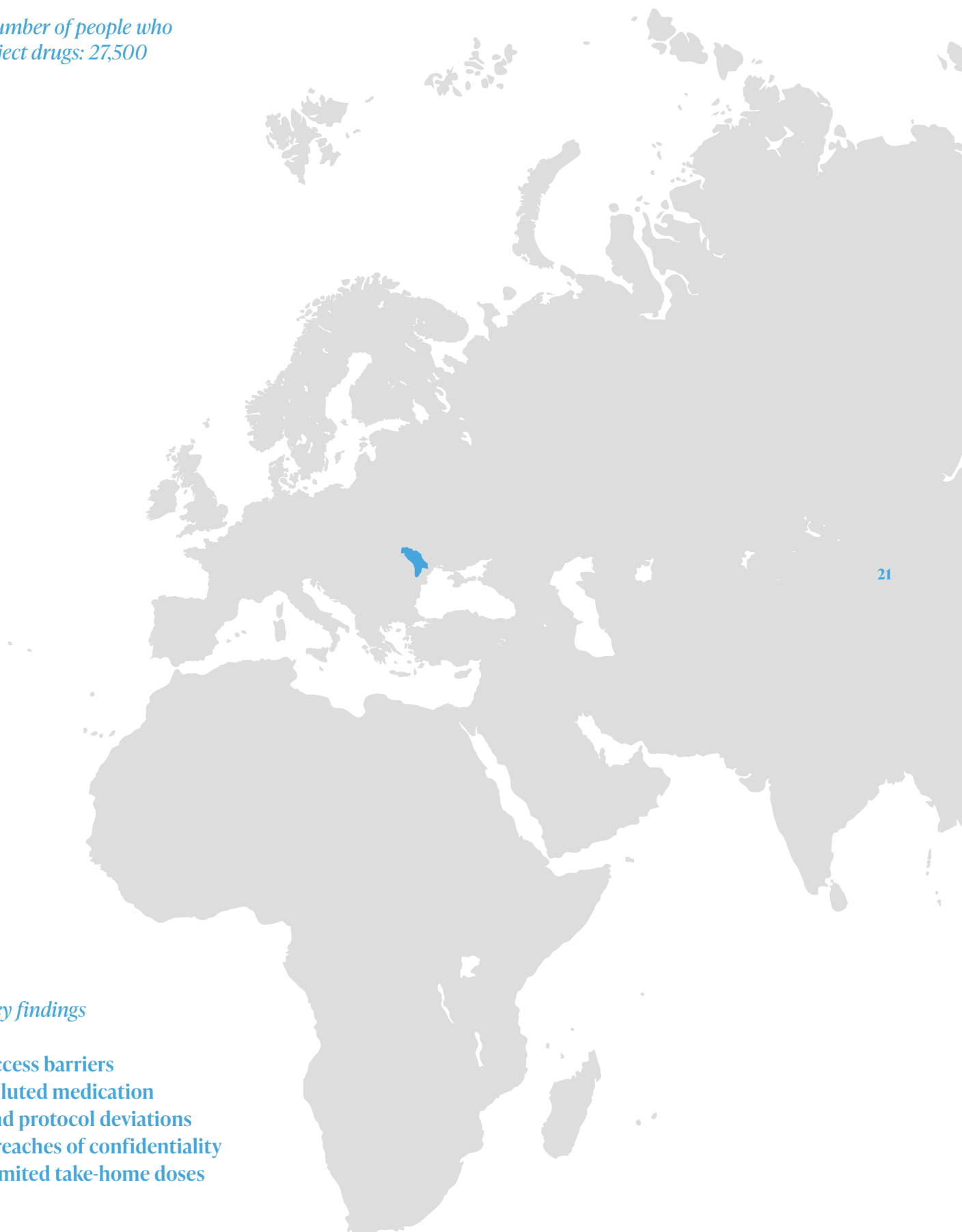
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“We continue our struggles and look for new ways to achieve results. But it will be very challenging, especially without the support of international organisations. International assistance in dialogues is crucial for OAT programmes issues.”



Moldova

*Number of people who
inject drugs: 27,500*



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Key findings

Access barriers
Diluted medication
and protocol deviations
Breaches of confidentiality
Limited take-home doses

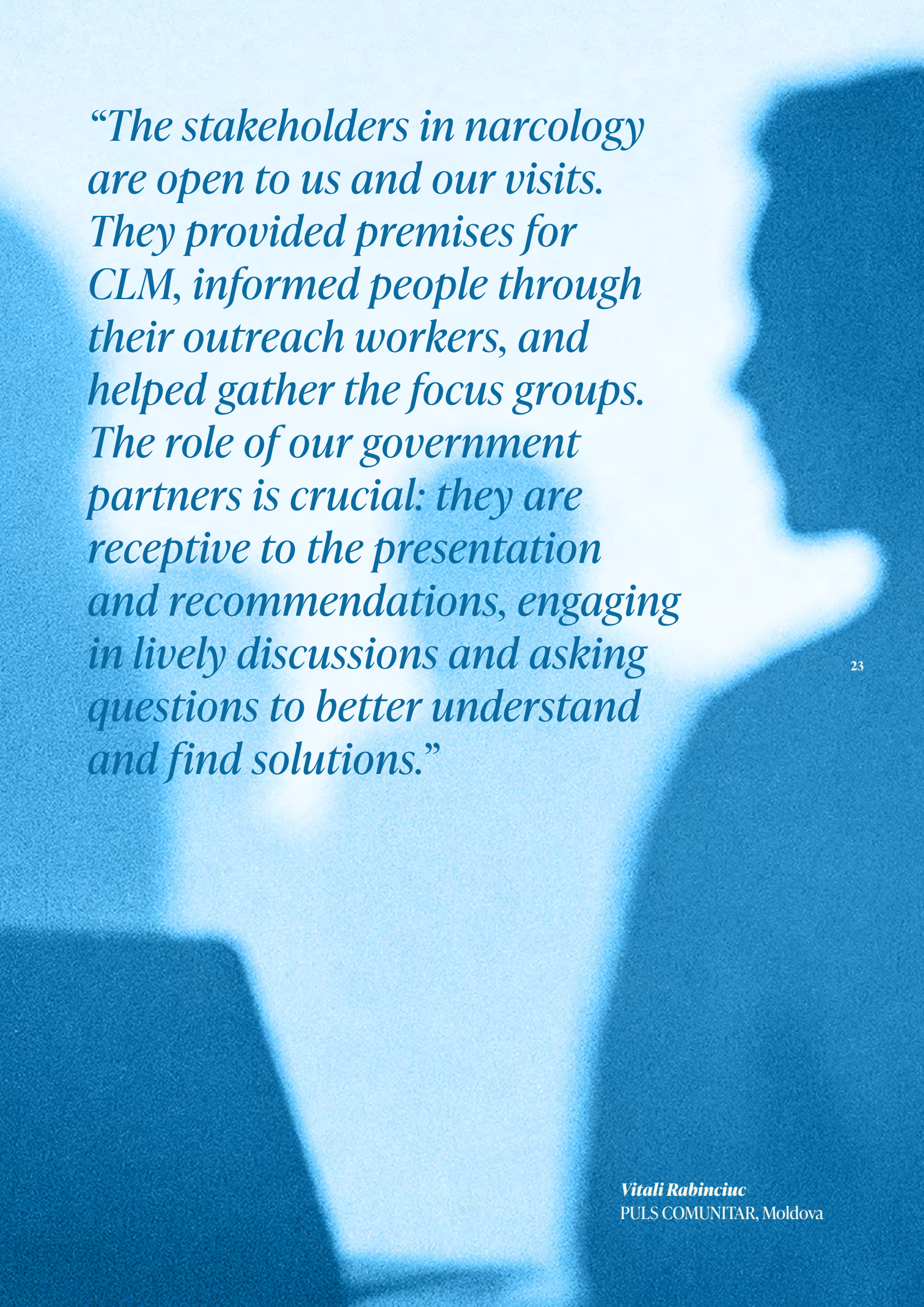
Moldova presents a compelling case where political conditions favour change. The CLM project used a survey approach, complemented by focus group discussions (FGDs) in smaller towns. These activities not only gathered data but also had a mobilising effect, engaging with community members directly. The CLM not only unveiled critical gaps in the OAT programme but also catalysed significant advocacy efforts aimed at addressing these challenges. The findings focused on four areas and provided a roadmap for improving patient care and programme effectiveness.

- *Access barriers:* Despite OAT coverage across nine sites, geographic disparities persist in Moldova. Rural patients struggle with long travel distances, and restrictive operating hours of clinics limit accessibility. At some sites, only methadone was offered to patients, even though buprenorphine was procured with public funds. Alarming, only four sites offered buprenorphine, restricting the patient's choice of their medicine. Some sites unofficially imposed restrictions requiring patients to arrive no later than one hour before closing time.
- *Diluted medication and protocol deviations:* Patients in certain sites reported diluted methadone and halving the dose, undermining treatment efficacy. Often, patients were lacking information about their treatment. Non-compliance with treatment protocols, such as the absence of psychosocial support, further compounded challenges.
- *Breaches of confidentiality:* Confidentiality violations were prevalent, especially in urban areas where medications were dispensed through windows in public areas, streets, and entries to medical facilities; at some sites, security guards and video surveillance were present. With no direct doctor-patient contact, this practice exposed patients to stigma from passersby and police officers, who regularly brought individuals to the same facility for alcohol and drug addiction tests. This discouraged treatment adherence, as patients were unable to discuss side effects.
- *Limited take-home doses:* The reversion to daily clinic visits ignored the pandemic's success with take-home medications in OAT programmes, which successfully reduced barriers and improved patient outcomes. Now, the advocacy goal is to establish and scale up take-home OAT. The existing OAT protocol provides this opportunity, but in practice, as in Tajikistan, it is almost unused. The CLM also uncovered an unintended consequence of salary metrics for doctors based on the number of patients received, discouraging the expansion of take-home medications.

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The key CLM-based recommendations in Moldova – summarising over 30 recommendations made – suggested that:

- Efforts to expand access to OAT should focus on ensuring patient-centred care through greater flexibility and accessibility. This includes offering a wider



“The stakeholders in narcology are open to us and our visits. They provided premises for CLM, informed people through their outreach workers, and helped gather the focus groups. The role of our government partners is crucial: they are receptive to the presentation and recommendations, engaging in lively discussions and asking questions to better understand and find solutions.”

range of medications, such as methadone and buprenorphine, at all OAT sites and aligning service delivery with patients' needs by extending operating hours, including weekends and evenings. Integrating OAT into primary healthcare services and distributing medications through pharmacies could further enhance accessibility, especially for those in underserved areas. Collaboration with private medical institutions, alongside legislative reforms, would improve service quality and broaden the geographic reach of OAT programmes. Moreover, innovative approaches, such as remote treatment supported by video technology, could address persistent barriers and make treatment more accessible to those in need.

- To improve the quality and effectiveness of treatment, standardised protocols and regular evaluations of healthcare providers should ensure consistency and efficacy across all sites. Treatment plans should be individualised and adapted to patient needs, with reduced waiting time to qualify for take-home self-administered doses, all to increase adherence and improve quality of life. Comprehensive care must encompass pharmacological and psychosocial support, delivered in a confidential and accessible environment. Adequately staffed OAT sites – with narcologists, peer counsellors, social workers, and psychologists – would facilitate this holistic approach, ensuring both personalised treatment and effective monitoring of service delivery. Optimising drug dispensing procedures and moving away from rigid and impersonal practices would further align OAT with best practices from other treatment models, such as HIV and tuberculosis care.

- Establishing robust monitoring and feedback mechanisms is essential to ensure continuous improvement. Systems for tracking adherence to treatment protocols, collecting patient feedback, and assessing service quality would allow for targeted enhancements. A centralised body could coordinate these efforts, introducing additional evaluation metrics such as patient satisfaction and successful reintegration outcomes. Strengthening pharmacovigilance at all OAT sites would also improve medication safety and reliability.

- Efforts should also focus on empowering patients with knowledge about their rights and how to address potential violations, supported by unified feedback tools and transparent communication channels. Confidentiality safeguards must be audited and reinforced to build trust in the programme, while electronic accounting systems could facilitate continuity of care for mobile patients. Training for law enforcement on their roles in supporting OAT programmes and ensuring non-discriminatory practices would help mitigate stigma and foster a more supportive environment for patients. Finally, enhancing the role of national coordinating bodies would ensure cohesive and effective management of OAT programmes across regions.

Pathways to change

These findings galvanised advocacy efforts targeting policy reforms. Advocacy wins in Moldova, and stakeholder engagement started with presenting findings to the MoH at the Global Fund CCM meeting and the Parliament through the Parliamentary Platform on Health in the State's Response to the Needs of People Who Use Drugs, pushing for expanded access to take-home doses and flexible clinic hours. As for the system changes, the advocacy led to the introduction of buprenorphine at two additional sites, with commitments for further expansion. As a primary goal of empowering the community via implementing CLM, patients reported getting educated on their rights, bolstering their ability to advocate for better services.

Stakeholders' buy-in was crucial. Initially sceptical, national and local actors recognised the value of CLM data, integrating it into decision-making processes. This partnership-driven approach ensured the recommendations resonated with policymakers and service providers alike. Based on the feedback from CLM, visits were conducted to study the experience of OAT programmes, a draft order was prepared, and the possibility of expansion to four more cities is being explored. The use of buprenorphine at two sites has already begun, with two more sites remaining to introduce this therapy.

The follow-up activities in 2024 highlighted new challenges: an unintended consequence of salary-based metrics for doctors counting patients served discouraged the expansion of take-home medications. In other words, the more people move away from daily visits to the clinics, the lower the doctor's salary. The CLM results were delivered to the National Health Insurance Company, but the final solutions are in the hands of the Ministry of Health. Further inquiries are planned regarding the provision of buprenorphine and methadone, as well as a study of physician payment metrics and systems in other countries.

It was anticipated that the number of individuals receiving take-home medications would increase. However, despite the distribution of take-home medications, many patients who previously collected their doses weekly have now been moved to a twice-weekly schedule, which is a clear step backwards. This change has sparked complaints from patients, who understandably find it easier to visit just once a week. Although daily visits have not been reinstated, the revised schedule remains inconvenient and burdensome for many. Thus, sustaining CLM efforts in Moldova is essential to ensure these issues are addressed effectively.

Moldova's CLM experience underscores the potential of community-led initiatives to drive policy and practice changes. The project has set a precedent for integrating CLM into national health strategies by mobilising patient voices and fostering partnerships. Moving forward, securing sustainable funding, addressing workforce shortages, and embedding confidentiality protections into protocols will be critical to success.

Vitali Rabinciuc

PULS COMUNITAR, Moldova

"We always strive to build partnerships to show that it benefits everyone. It helped that we were seen as partners in Parliament, working groups, and the drug policy commission under the Ministry of Internal Affairs."

Kazakhstan

*Number of people who
inject drugs: 79,900*



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Key findings

Access barriers
Unstable medication supply
Inconsistent care
Stigma and discrimination
Hospitalisation challenges

In the past decade, the community of people who use drugs in Kazakhstan has been pushing for the provision of take-home OAT medication and its availability in hospitals and places of detention. The most recent CLM initiative included surveys, interviews, and video testimonials demonstrating OAT's impact. It uncovered challenges in OAT programmes that are both not new and systemic, providing a roadmap for advocacy and reform.

The key findings focused on the following areas:

- **Access barriers:** Patients often face long travel times to OAT sites (1–1.5 hours each way) and limited operating hours (8–10 a.m.), making it difficult to balance treatment with employment or other responsibilities. It is illustrative that 14 informants out of 21 discontinued treatment due to interruptions in the supply of medication at the state level. Registration and identity papers are required, but not all people who use drugs have them. The waiting time from application to inclusion in the OAT ranges from one day to nine months. Centre infrastructures are not suited for people with disabilities (no elevators and multiple stairs to climb to access care).
- **Unstable medication supply:** Supply interruptions at the state level have led people to temporarily discontinue treatment, including those who participated in the study, undermining community trust and treatment adherence.
- **Inconsistent care:** Despite a national clinical protocol emphasising both psychosocial and pharmacological care, many patients were unaware of available psychosocial support. Only 5 out of 21 participants had copies of their signed treatment agreements, reflecting poor communication and documentation practices.
- **Stigma and discrimination:** Patients frequently encountered judgmental attitudes and inadequate privacy at OAT sites, which deter participation and affect treatment adherence.
- **Hospitalisation challenges:** Methadone is unavailable outside dispensing sites, preventing patients from seeking inpatient treatment for co-occurring health conditions.

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Based on these findings, the CLM initiative advocated for changes, such as:

- **Improving accessibility:** Expand OAT site operating hours, offer a broader choice of medications like buprenorphine, prevent treatment supply interruptions, and ensure facilities provide privacy, accessibility, and better accommodations for individuals with disabilities.

- **Ensuring take-home doses:** Develop standardised mechanisms for dispensing take-home doses and delivering medication to hospitals and detention facilities to ensure continuity of care.
- **Enhancing support:** Integrate psychological counselling and peer-to-peer mentoring into OAT programmes to reduce anxiety and stigma and provide comprehensive care. Improve OAT care by ensuring access to hepatitis C treatment, tailored prescriptions, and lab referrals. Integrate mental health screenings, peer counselling, and family support programmes to build trust and strengthen patient relationships while safeguarding confidentiality and dignity.
- **Strengthening oversight:** Implement robust performance indicators for OAT programmes, including measures of patient quality of life and treatment outcomes, to identify gaps and ensure accountability. Regularly collect patient feedback.

The report also called for advancing policy reforms or abolishing mandatory drug users registry (narcological registry), which perpetuates unemployment and social exclusion for people who use drugs.

The results of the monitoring and accompanying recommendations were presented to stakeholders at a CCM meeting in late 2023 and early 2024. CCM members proposed aligning the recommendations with relevant professional domains. Subsequent steps involved analysing and compiling a list of legal and regulatory documents related to existing directives. Based on this analysis, the community sent formal requests to the MoH of Kazakhstan, the Republican Centre for Mental Health, and NGOs working with people who use drugs, asking them to review the recommendations and provide feedback on potential implementation. If ever obtained, the formal responses largely lacked substantive engagement with the proposed changes. Again, issues such as inadequate methadone supply, opposition from law enforcement, and stigma surrounding OAT have hindered progress. Additionally, the transition of OAT funding to the state budget in 2024 has not expanded patient coverage or improved programme quality, with a sharp decline in participants. In the meantime, community groups engaged in due order in correspondence with government agencies, underscoring the need for continued advocacy and legislative reform to ensure access to and sustainability of OAT programmes.

Pathways to change

A key pathway involves building the capacity of community representatives within the CCM, ensuring they are equipped to articulate priorities, analyse materials, and effectively advocate for solutions. Regular consultations and targeted discussions during CCM sessions have the potential to systema-

tically address pressing issues such as decentralisation, procurement challenges, and service accessibility, embedding CLM findings into actionable policies.

Efforts to institutionalise CLM in Kazakhstan have gained momentum in 2024, with structured CLM mechanisms in the current three-year GF grant having a national CLM coordinator and eight representatives of key populations as sub-coordinators who are expected to maintain contacts with communities and outreach workers. In other words, the function of CLM is currently assigned to sub-coordinators, inclusive of people who use drugs and service providers at the grassroots level. It marks a significant step forward,

Ryssaldy Demeuova
CCM Secretariat Coordinator,
Kazakhstan

“Community representatives need to recognise their role as decision-makers within the CCM. Their voice directly impacts the lives of people in remote areas who promoted them as a CCM member from relevant community and voted for them, and preparation stage before CCM meetings is a key to fulfilling this responsibility.”

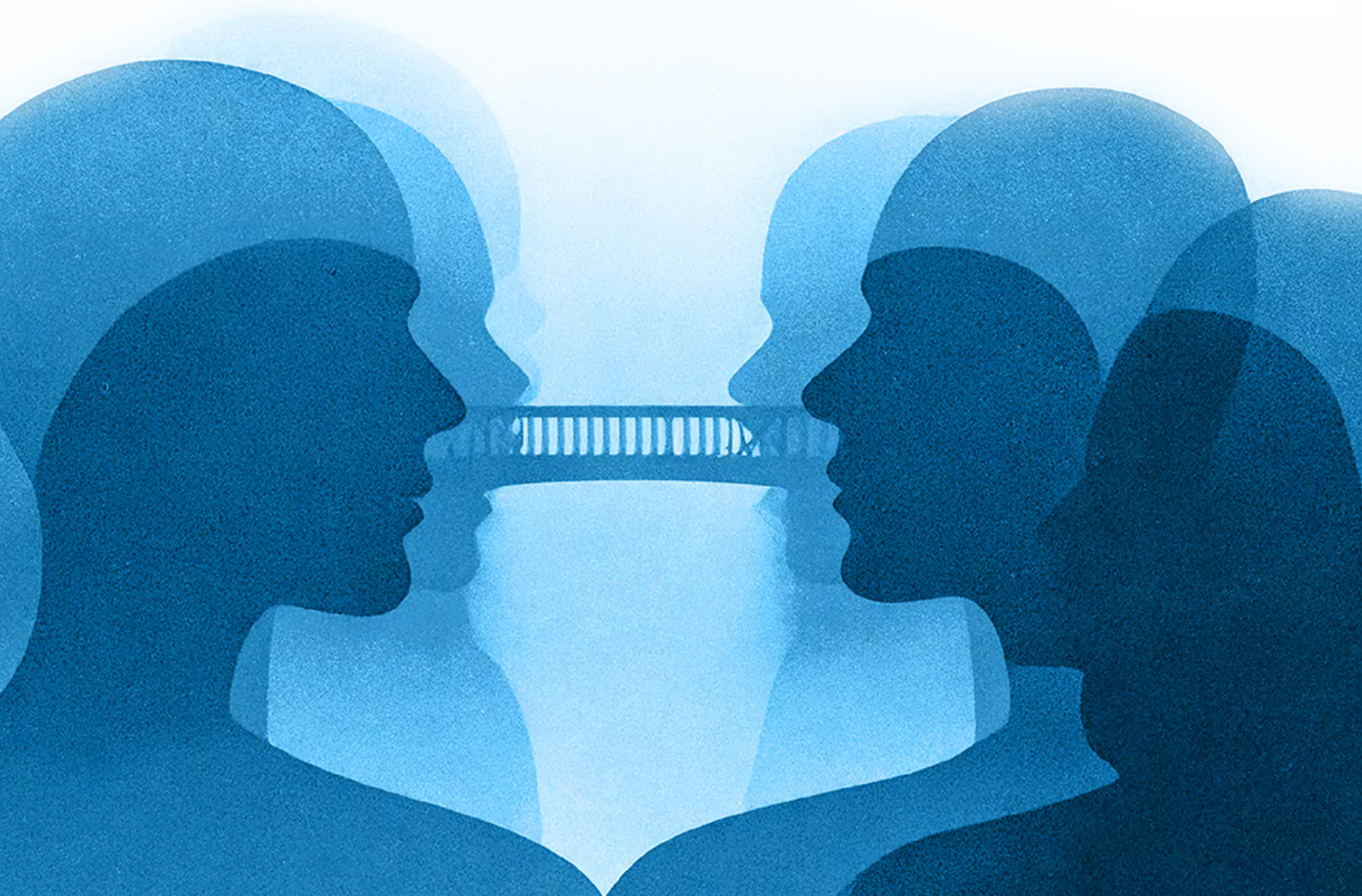
and community perception is that the next priority for CLM is trust points for people who use drugs. Some sub-coordinators may benefit from additional capacity building as their roles and responsibilities continue to expand alongside their growing level of engagement.

The CCM in Kazakhstan offers several forums that could play a role in advancing the voices of people who use drugs. Notable among these is the Key Affected Populations (KAP) Platform, with its twenty-eight community representatives, inclusive of people who use drugs, reporting being successful in leveraging community suggestions for the GF proposal. The second tool is the CLM working groups supported by a liaison expert

council, channelling community input into coherent proposals and reducing tensions by directing issues to the appropriate authorities. The KAP Platform and the working groups provide opportunities for communities to share their concerns, articulate findings, and influence policy. The CCM oversight visits present another important advocacy opportunity based on CLM results, as these visits usually engage with the community.

However, the most logical and impactful moment for communities to step in is during the preparatory exchange prior to the CCM meetings, where issues can be raised and refined in advance to streamline discussions and focus on actionable issues. It may ensure that non-CCM members and responsible government agencies are invited to address specific concerns directly at the CCM meetings. This approach has the potential to ensure accountability and efficiency, with decisions incorporated into meeting protocols and tracked for implementation. For Kazakhstan, it is vital to bridge the language barriers and improve training for Kazakh-speaking populations and decision-makers, as well as critical steps toward broadening participation and strengthening advocacy for OAT programmes among the most conservative opponents.

Despite initial resistance to the idea of CLM, the community has proven instrumental in presenting their findings, which were received as community-led research, providing a space to voice proposals through nominated representatives. Stakeholders noted that they were unaware the initiative was funded by the Global Fund, which could have prompted a stronger level of follow-up and engagement with the recommendations. As required, the recommendations were thoroughly organised and distributed to three organisations responsible at different levels, with formal letters sent and generic or absent responses received. In any case, the collaboration with government ministries and local authorities demands enhanced skills from the community, including navigating complex policy environments within and outside CCM and communicating effectively across sectors. It raises concerns about the reliance on community members as volunteers. Without adequate support, training, resources, and fair remuneration for their work, expectations may exceed what these representatives can realistically deliver while avoiding burnout and frustrations. To address this, a greater investment in capacity-building and support mechanisms is essential to ensure community members can contribute meaningfully without being overstretched..



Kyrgyzstan

*Number of people who
inject drugs: 17,379*

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Key findings

Limited access to OAT
Challenges in take-home doses
Confidentiality issues
Increased safety

While the OAT programme in Kyrgyzstan has demonstrated stability over the years, the monitoring identified systemic issues that may further improve its effectiveness and accessibility. The CLM initiative revealed critical insights into the OAT programme, driving both advocacy and tangible changes.

- *Limited access to OAT:* Geographic disparities persisted, with some regions lacking equitable access to OAT services. Sites in smaller towns often struggled to maintain services due to low patient numbers, leaving patients underserved. The programme's reliance on methadone without alternative restricted patient choice. Daily site visits for methadone doses were seen as inconvenient by 86.8% of the respondents in the 2022 CLM survey. Although most respondents (52.63%) benefit from take-home methadone for 4-5 days, a majority (73.7%) expressed a desire for more choice between methadone and buprenorphine. The five-day limit is due to methadone being diluted, which restricts its shelf life to just five days. This highlights the need for a tablet form of the medication.
- *Challenges in take-home doses:* During the pandemic, take-home methadone doses proved effective, reducing patients' logistical burdens. However, post-pandemic regulations reverted to more restrictive practices, limiting the ability to implement this model widely. Concerns about methadone diversion into the black market further complicated the situation.
- *Confidentiality issues:* Breaches of patient confidentiality at OAT sites were reported, with some services compromising privacy due to poor infrastructure or operational practices. These breaches undermined trust in the programme and discouraged participation.
- *Increased safety:* The findings revealed significant insights into the safety and satisfaction levels within the OAT programmes, alongside key areas for improvement. While 52.6% of respondents perceive OAT sites as safe, safety concerns persist, with 100% of participants advocating for the removal of drug users registry to enhance programme security. Fear of police affects 7.89% (3) of respondents, and stigma and discrimination – often linked to police interactions – were reported by a more substantial 52.6% of respondents.

The CLM findings spurred significant advocacy efforts, leading to notable changes such as the expansion of treatment options with plans to introduce buprenorphine and its long-acting formulations into OAT protocols in 2024. Advocacy efforts also prioritised introducing long-acting buprenorphine, supported by webinars that connected local stakeholders with international peers experienced in its implementation. From the outset, the community group cooperated closely with the Republican Centre for Psychiatry and Narcology (RCPN). These included, with other NGOs, securing funding to establish peer-to-peer counsellor and social worker positions at each OAT site and advocating for the inclusion of methadone tablets and buprenorphine

in the state budget under the State Guarantee Programme. The quota for buprenorphine has been received for procurement. All steps taken in this promising development include the introduction of buprenorphine and BUVIDAL in 2025, with more time needed for methadone in tablets. Community plans are underway for a CLM initiative on buprenorphine, funded and supported by ENPUD. Additionally, the country is set to participate in a study on BUVIDAL, with preliminary plans and survey templates already being developed by the community. Additionally, digital tools, such as Telegram bots and mailing lists, were introduced to provide information on overdoses, patients' rights, methadone, and buprenorphine. In the summer of 2024, Peer to Peer organised training programmes for OAT community organisations and participants, incorporating international best practices with a focus on naloxone and buprenorphine use. These coordinated efforts marked a significant step toward improving the accessibility, safety, and quality of OAT services.

The practice of “drug user registration” for OAT participants is being replaced by dynamic surveillance in the same service, all to improve safety and reduce stigma, but while the discussions are ongoing, the practical implementation in the employment market is unclear: the question remains whether records from the same Psychiatry and Narcology service but with dynamic surveillance will make a difference for patients.

CLM also suggested the dispensing of methadone through pharmacies and introducing methadone tablets to enhance availability. Even if certain measures, such as dispensing medication through pharmacies, do not yield immediate results, it is crucial to remain persistent and not lose sight of their potential.

Over the past two years, specialist availability has significantly improved at programme sites, with the addition of a surgeon, a general practitioner, and, more recently, psychotherapists. Due to the lack of funding to cover transport expenses, the sites reviewed their patient lists to identify those living in remote areas and suggested take-home doses for eligible individuals who met the required criteria. These new positions, funded through international support, aim to address critical gaps in care. Social workers and peer counsellors have also been added to the sites. OAT sites were implemented in the summer of 2024 for peer counsellor training and integration, as per CLM recommendations. The country also expects an updated OAT protocol to address CLM recommendations and enhance take-home doses.

In other words, CLM led to revisions in treatment guidelines, incorporating patient-centred approaches and addressing dosage inconsistencies. However, challenges persist – on some sites, social worker positions were filled, but the workload is offloaded onto peer counsellors. Staffing remains a broader

Sergei Bessonov
PEER TO PEER, Kyrgyzstan

“The key now lies with the experts in working groups, where there are still requirements for civil society representatives to contribute to document development.”

issue, with vacant doctor positions going unfilled for months due to shortages and some doctors expressing frustration over limited resources. They have highlighted the need for regular peer-led counselling groups, which are not currently supported financially and rely on community organisations for implementation. Doctors are interested in using CLM as a bridge between the community and their programmes to improve service quality.

Ayzada Usenakunova, MD
Republican Centre for Psychiatry
and Narcology, Kyrgyzstan

“The issues our clients share with peer counsellors or social workers often don’t reach us, yet they are crucial. The community acts as a bridge, bringing this information to our attention – for instance, highlighting gaps in available services.”

Key issues include expanding access to pre-contact prophylaxis (PrEP) and identifying barriers that prevent patients from utilising newly introduced psychotherapist and detox services. While the latter are a step forward, ensuring effective use and popularity among OAT patients remains a pressing concern.

The CLM implementation faced significant hurdles, particularly within the restrictive political and legal environment. The introduction of NGO laws in 2023 created bureaucratic barriers, complicating engagement with state institutions and delaying community-driven recom-

mendations. Additionally, tensions with stakeholders, such as UNDP, highlighted the importance of independent, community-led initiatives. To address these challenges, stakeholders suggest it would be beneficial for the key funding organisation, such as the Global Fund, to find an aligning mode of action with the government and implementing partners, ensuring a coordinated approach that can also incorporate community groups. Such alignment would help avoid duplication or overlap of activities, maximising efficiency and impact.

Despite these obstacles, Peer to Peer presents its first CLM initiative, which is entirely implemented by the community with an emphasis on the value of local expertise and patient input and the RCPN shaping effective interventions. Though constrained by limited geographic coverage and funding, the CLM findings were quickly taken up by the RCPN partner, sparking productive dialogue within healthcare and leading to improvements in service delivery. Thus, in Kyrgyzstan, a community equipped with CLM data has had an impact and fostered day-to-day collaboration with the RCPN, amplifying patient voices. While these efforts have driven day-to-day improvements in OAT services, policy recommendations continue to face obstacles, highlighting the need for sustained advocacy and investment in community capacity to overcome barriers and secure long-term advancements.

Tajikistan

*Number of people who
inject drugs: 18,200*

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Key findings

Access barriers
Psychosocial support gaps
Stigma and negative interactions
Daily attendance requirement
and fatigue
No access to pre-trial centres

This CLM initiative also revealed critical insights into the experiences of OAT participants in Tajikistan as an initiative group called Intihob, supported by SPIN Plus, documented the profound impact of gaps in OAT services on patient adherence and well-being. The findings underscored the urgent need for systemic reforms to improve the quality of OAT patients and their adherence to treatment.

The key findings focused on the following areas:

- *Access barriers:* The complexity of transport links and daily transportation costs presented a barrier, especially considering that most patients do not work due to the requirement to provide a certificate from a drug addiction service for employment. Many rely on precarious daily earnings as part-time workers due to the site's opening hours from 8 am to 12 pm, making consistent programme participation challenging as these patients continue to struggle to pay for daily transport.
- *Psychosocial support gaps:* Psychological services for OAT participants are virtually non-existent, leaving patients to navigate their recovery without structured emotional support. This gap exacerbates mental health issues and increases co-dependency on self-administered pharmacy drugs.
- *Stigma and negative interactions:* Participants frequently reported discriminatory attitudes from OAT programme staff, harassment by local residents, and the lack of welcoming spaces at OAT sites. These issues undermine the trust and dignity of patients who do not have benches or chairs to sit down when waiting in line. The informants said they lack safe places for peer support and community initiatives where they can sit and talk after they receive the medication.
- *Daily attendance requirement and fatigue:* Take-home methadone doses remain inaccessible to stable patients despite being authorised in national protocols. Law enforcement and healthcare professionals resist its implementation, citing that the storage of these doses constitutes an offence on the one hand and fears of misuse and legal repercussions on the other hand. Thus, the procedure remains largely unutilised. Institutional resistance and administrative inertia have prevented the policy from being put into practice, depriving patients of a critical opportunity for flexibility and an improved quality of life, such as maintaining employment, visiting family in other regions, or supporting elderly relatives. The lack of medical personnel also exacerbates access barriers, which can be resolved by distributing doses in pharmacies by prescription.
- *No access to pre-trial centres:* Additionally, there is no OAT access in pre-trial detention centres, denying therapy to arrested individuals who were enrolled on the programme prior to arrest. However, key informants confirmed there is a possibility that a detainee will be transported to the dispensing OAT site.

“Community-led monitoring should be driven by the community itself, but here lies the challenge – we lack the strength within our community. Activism is fading; the energy is dulling, and people seem increasingly indifferent. The older generation of activists is aging out, and there’s little sign of new ones stepping up. To move forward, we need to elevate this to a level where the patient community is genuinely invested, ensuring quality services and breaking the cycle of stigma. Stigma has become so ingrained that people accept it as normal – ‘this is just how people who use drugs should be treated.’ We must disrupt this mindset and foster real development within the community.”

Based on these findings, the initiative proposed several actionable recommendations:

- ***Flexible access to OAT:*** The ultimate goal of CLM advocacy was to initiate and expand the provision of take-home medication for OAT, a practice permitted under existing legislation but largely unimplemented in reality. Achieving this requires the establishment of mechanisms for dispensing and monitoring medications that enable patients to manage their treatment at home. To improve accessibility, the introduction of mobile clinics could bring services to remote areas while addressing legislative gaps to allow for more flexible applications of OAT. Additionally, given the shortage of drug addiction doctors, issuing prescriptions for OAT medications should be considered as part of a broader strategy to enhance the programme's reach and effectiveness.
- ***Legislative advocacy:*** Another challenge is that the regulatory framework is structured in a way that places patients in a deliberately subordinate position, preventing them from fully asserting their rights due to the risk of being excluded from treatment. The suggestions from this grassroots initiative are as follows. Resolving this long-standing issue requires sustained efforts to empower patient communities and bolster their advocacy for patient rights and stigma reduction toward people who use drugs. A critical component is revising OAT regulations to align with international standards and evidence-based practices, particularly concerning programme exclusion criteria and access to take-home medications. The second suggestion concerns patients' options for treatment: engage policymakers to include buprenorphine in the OAT programme and streamline legal requirements for its import and distribution.
- ***Capacity building:*** Invest in community-led advocacy and monitoring, ensuring that representatives are equipped to influence policies and evaluate service delivery. In Tajikistan, capacity building among community members yielded mixed results. While training and surveys were conducted, the lack of robust advocacy undermined systemic change. Challenges included limited financial and organisational resources for the community of people who use drugs, compounded by bureaucratic obstacles.
- ***Psychological and peer support:*** Establish psychosocial support systems, including counselling and self-help groups, to enhance patient resilience and adherence.

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Pathways to change

The Intihob initiative highlighted the importance of community ownership and sustained advocacy. However, it also revealed deep-seated challenges, including the erosion of community activism. The interviewed OAT patients

expressed daily fatigue, and newer members struggled to engage in technical and policy-related discussions. Efforts to strengthen community involvement must address this gap by fostering a new generation of advocates and ensuring their voices are integral to decision-making.

Despite the thorough data collection, development of detailed recommendations, and presentation at relevant CLM meetings and roundtables, the process has reached a legislative and institutional impasse. While there is a broad acknowledgement of the need for take-home methadone, implementation is obstructed by complex legal constraints. Law enforcement agencies remain opposed to the idea, citing concerns over drug storage and potential misuse. Healthcare professionals, too, are hesitant, fearing liability if patients are apprehended in possession of medication issued under their supervision. Another observation by Intihob is limited funding for OAT programmes, particularly from domestic sources that stymie progress. Similarly, progress on expanding OAT access in pre-trial detention centres has been stalled, even though infrastructure improvements, such as renovated rooms, have been made. These challenges highlight the disconnect between theoretical agreements and practical realities. The OAT programmes remain heavily reliant on international donors, reducing incentives for government-led investment and oversight. As noted by community holders of these findings, donors and implementers must align their

goals with community priorities, avoiding top-down approaches that risk alienating grassroots stakeholders. While donor funding sustains the programme, key government agencies, including the Ministry of Health, demonstrate little urgency in addressing these systemic issues, reflecting a consumerist approach to externally funded initiatives.

Ultimately, while the CLM initiative in Tajikistan provided valuable insights, achieving meaningful engagement of people who use drugs, change will require collaborative, long-term efforts to dismantle systemic barriers and empower community-led solutions. Efforts to advocate for sustainable solutions are ongoing in Tajikistan, with partners organising resolutions, roundtables, and presentations. CLM has been integrated into national efforts supported by a Global Fund grant and implemented in collaboration with USAID. SPIN Plus has independently initiated CLM in prisons, with pilots planned in one or two facilities to evaluate its long-term feasibility and with anticipated results by mid-2025. As part of this initiative, a paper-based questionnaire has been co-developed with the Health Advocacy Coalition. However, without stronger community representation and engagement in decision-making, the potential for meaningful change remains limited: a renewed focus on empowering patient communities and fostering genuine collaboration with all stakeholders will be essential for overcoming these entrenched obstacles.

Common Trends

Common Trends

The CLM initiatives of OAT programmes across the five countries reveal striking commonalities and shared challenges. At its core, CLM places communities at the heart of service evaluation, leveraging their lived experiences to identify systemic barriers, advocate for change, and, in some countries, for reforms. Despite varying political and social contexts, the initiatives consistently focused on empowering community grassroots organisations to monitor OAT services. This demonstrates that local engagement is critical to uncovering gaps in OAT programming and, potentially, in harm reduction programmes.

In each country, capacity-building efforts underpinned the monitoring process. Training sessions and webinars equipped participants with essential data collection and advocacy skills. OAT services emerged as a central focus, reflecting their critical importance and the widespread deficiencies in access, such as restrictive policies and limited take-home doses. These barriers were echoed across the region, underscoring the systemic nature of the challenges facing OAT efforts.

While the methodologies varied – from surveys and focus groups to diary entries – the initiatives shared a broader objective: to make community voices indispensable in shaping OAT policies. In practice, this fostered data collection and a sense of ownership among communities, many of which consequently became more engaged in advocacy. Yet, the ultimate effectiveness of CLM depended heavily on political will, institutional flexibility, and the extent to which decision-makers valued community input.

The political landscape, however, significantly influenced outcomes. With its supportive political environment, Moldova saw CLM results contribute to policy discussions and community mobilisation. By contrast, Kazakhstan's and

Kyrgyzstan's conservative policies curtailed advocacy efforts, limiting the impact of findings. Georgia's innovative use of participant diaries provided nuanced insights into daily struggles, but political instability stymied the translation of these results into actionable reforms. Tajikistan's context presents unique challenges as, at most CLM-related meetings, the absence of patient community representatives is glaring, with the spaces dominated by NGOs, donors, and government institutions. This lack of community involvement raises questions about the purpose of these initiatives – if the voices of those directly impacted are neither included nor empowered, what is the real value of these efforts? Across the three Central Asian countries, NGOs with little connection to the community take on the role of conducting CLM, often treating the process as a project rather than a tool for genuine community engagement and advocacy. Most efforts focus on providing services rather than building sustainable structures for advocacy and representation. In the meantime, CLM implementers in all five countries shared institutional barriers.

Donor constraints

Donor requirements often fail to account for local contexts, imposing rigid demands, calendar plans, and advocacy processes that strain community resources and are incompatible with local needs. Small grants' proportionate reporting was still too much of a burden compared to the amount of funding provided, deterring grassroots community organisations from actual advocacy and community-building work. Throughout the interviews for this report, the Global Fund's inflexibility in adapting to political instability was mentioned, particularly in terms of what is considered possible or not. Additionally, calendar delays in implementation by community organisations were noted, often due to factors beyond their control. At the same time, stakeholders brought to attention an

important retard in CCM meetings in Georgia and Kyrgyzstan that further highlights the disconnect with the donor requirements.

Community capacity

The misalignment between funding recipients and the communities being monitored is a recurring issue. Established organisations often secure grants due to their administrative expertise, relegating community groups to secondary roles. Communities lack core funding for premises and offices, in other words, for their own spaces and fair pay to their CLM implementers. This undermines the authenticity of community-led monitoring. Another challenge mentioned was the lack of researchers capable of data analysis from a community perspective. This gap highlights a broader issue: while sociologists can interpret data, they often fail to capture patients' nuanced realities, points of view, and concerns and look into less significant figures or issues while overlooking the individuals behind them.

Seen across countries, internal conflicts within communities, bullying of community leaders and comparing their work and opinions to each other, conflicts between service providers and beneficiaries, and fear of OAT patients raise acute issues because they risk being excluded from programmes or have problems exacerbating these challenges.

Programmatic gaps

OAT programmes, while critical, remain the most medicalised and detached from civil society. Community involvement in service provision is minimal, with little progress toward integrating peer consultants or creating patient-centred systems. Common themes in all countries focus on several areas, such as take-home doses vs daily visit requirements. This option is in place in Moldova and Kyrgyzstan, Kazakhstan and Tajikistan have registered no progress in this regard, and Georgia has been experiencing a step back. The reports highlighted persistent access gaps

related to transportation issues and remote areas, as well as complete inaccessibility in in-patient hospitals and pre-trial centres. They also noted a lack of psychological, peer, and employment support, alongside widespread stigma and discrimination at OAT facilities. On a practical level, narcological services at the national level appear open to and supportive of necessary reforms, with the capacity to implement these changes within short-term periods. However, advocacy efforts have hit the ceiling regarding policy shifts to allow take-home doses at the level of the Ministry of Health, law enforcement agencies, or initiatives requiring additional financial investment – such as psychological support and efforts to combat stigma among medical staff. Importantly, most recommendations arising from CLM have hinged on political-level changes, which remain largely unaddressed.

In summary, while the CLM initiatives shared common goals and faced similar challenges, the processes and outcomes varied significantly across the five countries, influenced by methodological choices, political contexts, and levels of community engagement and influence. Despite the challenges, CLM has proven its value, particularly in mobilising communities of people who use drugs and highlighting system-ic inequities in OAT programmes. These countries' collective experience demonstrates CLM's transformative potential when communities are genuinely empowered. However, it also underscores the importance of political context, as systemic resistance can undermine even the most robust grassroots efforts without impacting policies. As OAT initiatives evolve, integrating community perspectives will remain vital for addressing entrenched challenges and advancing equitable access to services.

“If the goal of donors and networks is to support the community of people who use drugs, then both the process and outcomes must align with its interests, free from bureaucratic constraints or imposed criteria. Otherwise, it should be acknowledged openly that the initiative is donor-centric and managed by NGOs meeting donor requirements. To restore the authenticity of community-driven efforts, we need to revisit the approaches of a decade ago – focusing on developing knowledgeable and empowered community representatives who can genuinely lead and shape their own advocacy and monitoring initiatives.”

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Country-Level Similarities and Differences

In process



Community engagement:

In all countries, local communities actively participated in monitoring OAT services, selecting focus areas and collaborating with professional researchers.



Capacity building:

Each initiative included training components, such as webinars and workshops, to enhance the skills of community members in data collection and analysis.



Advocacy intentions:

All the initiatives aimed to influence policy and practice by presenting findings to relevant authorities and seeking improvements in OAT service delivery.



Community mobilisation:

The monitoring process in Moldova and Tajikistan had a mobilising effect, engaging community members and fostering a sense of ownership. In Georgia, the diary method provided in-depth insights but faced challenges due to political instability affecting policy implementation. In all countries, it is essential to retain the expertise of community networks and NGOs supporting them to ensure the quality of the OAT programmes. It proved that capacity building for OAT programme participants built into the CLM initiatives led to more structured data collection and greater openness from participants.



CCM as a key forum:

All findings and recommendations were presented at the CCM in their countries. The CCM has been an excellent platform for interaction and direct exchange with healthcare decision-makers until recently when issues emerged regarding convening regular meetings and having enough space for discussions of CLM in OAT programmes vs other countries' priority issues.



Variety of methodological approaches:

Moldova held focus group discussions; Kazakhstan and Tajikistan turned to an interview method to gather qualitative data; Kyrgyzstan tried a patient survey in combination with several interviews, while Georgia implemented a diary-based data collection, with participants documenting daily experiences over one to two weeks. Kazakhstan produced video testimonies featuring OAT patients who openly revealed their identities.



Resource allocation to non-community actors:

Initiatives that were called and presented as CLM were performed by implementers outside the OAT programmes, resulting in methodological and findings weaknesses and contrasting to the critical policy-level community-owned CLM conclusions.

Country-Level Similarities and Differences

In results



Common barriers:

All countries identified obstacles in accessing OAT services, such as restrictive policies, limited availability of take-home doses, and logistical/ geographical challenges for patients.



Lack of core funding:

In Moldova and Kyrgyzstan, community groups of people using drugs currently do not have office premises, impacting their regular work stability, organisation representation, and opportunities to meet with broader community networks.



Advocacy outcomes:

Despite varying degrees of success, each initiative contributed to raising awareness among policymakers about the issues within OAT programmes. Most of the CLM-based recommendations require a policy shift.



Political context:

CLM in Georgia, Kazakhstan, and Kyrgyzstan faced significant political challenges, including pressure from law enforcement to do with NGO laws, which hindered advocacy activities. In contrast, Moldova's political environment was more conducive to community engagement. In Georgia and Kyrgyzstan, the CLM initiatives started under conditions that were highly conducive to change and filled with a sense of hope. However, they are concluding in dramatically different political circumstances. In Georgia, regulations on OAT have become significantly more restrictive. Meanwhile, in Kyrgyzstan, civil society can no longer engage and contribute as it once did due to the implementation of the laws on foreign agents and the media, which have curtailed the participation of citizens with effects only to await and observe in the future.



Public trust and engagement:

CLM offers significant benefits, particularly in fostering trust and inclusivity in policy development. When communities most affected by drug issues are actively engaged in shaping reforms, CLM ensures that policies reflect lived realities and address genuine needs. This participatory approach not only strengthens the effectiveness of reforms but also helps restore public trust in government institutions, especially where drug policies are perceived as overly punitive or ineffective.



Policy impact:

Moldova achieved notable progress, with findings leading to policy discussions and potential reforms. Conversely, in Kazakhstan, political resistance impeded significant changes.



Strengthening international partnerships:

Given the limited political will at the national level, donors, networks, and international and regional organisations are expected to play a crucial role in facilitating dialogue and supporting advocacy efforts.

Lessons Learnt for Other Countries and Communities

The experiences of EHRA-supported CLM of OAT programmes in five countries offer valuable lessons that are potentially transferable to other countries and communities that are seeking to implement similar initiatives. These efforts highlight both the potential of CLM and the structural and political barriers that must be addressed for it to succeed.

A key takeaway is the importance of capacity building as a foundation step. Equipping communities with the skills to gather, analyse, and present data is essential for ensuring the credibility and impact of their findings. Training programmes tailored to local contexts can help bridge knowledge gaps and empower participants to take ownership of the monitoring process. This empowerment not only enhances data quality but also fosters community mobilisation, a critical driver of advocacy.

Another lesson is the need for methodological flexibility. The diverse approaches employed – ranging from focus groups in Moldova to diary studies in Georgia – demonstrate the importance of adapting monitoring tools to suit local conditions. For instance, the patient diary approach provided compelling evidence that resonated with stakeholders. Tailored qualitative methodologies like focus groups can uncover nuanced barriers and provide actionable insights, making the data more compelling and complementing for policymakers. Participants reported that when they created questionnaires themselves, they did not immediately think about many aspects that were raised as priorities in the focus groups. Involving professional researchers can enhance the quality of data, but they must uphold community priorities and maintain their voice in advocacy.

For service providers, policymakers, and other stakeholders, CLM should be viewed not as a critique or information with a non-appreciative approach by (under)served communities but as an opportunity for collaborative problem-solving and co-creating solutions.

It offers a pathway to identify gaps, strengthen or add new services, and address broader systemic challenges such as accountability, civil participation, successfully delivering measurable results, and effectively reaching the beneficiaries for whom the programmes are intended.

However, these experiences also underscore the decisive role of political context. Countries with more open governance, such as Moldova, were able to translate CLM findings into policy discussions, while restrictive environments, like Kazakhstan, significantly limited the impact of community efforts. New appointments in the health programme leadership and new law initiatives stalled CLM efforts in Georgia, and there was limited discussion of CLM at open forums in Kyrgyzstan. For CLM to

Zaza Karchkhadze
RUBICON, Georgia

“We would recommend other countries to use patient diaries, as this method brings a strong emotional impact. Communities in other countries can replicate it effectively and benefit from it.”

thrive, it must be supported by political will and institutional receptivity to community input. Advocacy strategies must, therefore, include a constant and uninterrupted building of alliances with policymakers, OAT service governance, and other stakeholders in any form where direct presence and person-to-person interaction are possible. Many more discussions need to be run in forums with online and physical presence of decision-makers to ensure that findings lead to actionable reforms.

Looking closer to the successful example of Moldova, the CLM project also faced several hurdles, from the lack of funding and office space for the community implementor to resistance from some healthcare providers when decisions were made on the national level. An unexpected barrier was the salary-based performance metrics for OAT site doctors, linking the size of their salary with the number of patients, which inadvertently discouraged patient-centric practices like take-home medications, leading to fewer patients on-site daily. However, the perseverance of PULS Comunitar and its partners demonstrated the power of collaboration. The inclusion of diverse voices – patients, healthcare providers, and policymakers – ensured a holistic approach to problem-solving. Dealing directly and openly with the challenges that were there, the CLM initiative in Moldova took the lead as a game-changer for OAT services, transforming patient feedback into actionable change. By addressing systemic barriers and fostering collaboration, it has laid the groundwork for a more inclusive, effective, and patient-centred approach to addiction treatment.

Finally, the experiences highlight the dual purpose of CLM: generating evidence for policy change and mobilising communities. Successful initiatives not only produce data but also strengthen the collective voice of people who use drugs and people who receive opioid agonist treatment, positioning them as key actors in shaping OAT programmes. For other countries, integrating these dual

objectives into CLM design can maximise both immediate advocacy outcomes and long-term community empowerment.

Expanding CLM to harm reduction efforts – such as needle and syringe programmes – faces similar barriers, with inadequate resources and limited independent oversight. Future efforts to monitor needle and syringe programmes would face additional challenges, particularly ensuring freedom from conflicts of interest and the ability to form well-informed opinions on harm reduction services. It is especially crucial given the extensive involvement of the community in service provision within this area.

Ultimately, these lessons suggest that the success of CLM depends not only on the tools and resources provided but also on fostering an enabling environment where community voices are valued and integrated into decision-making. By learning from these experiences, other countries can design CLM initiatives that are both context-sensitive and transformative. The restrictive legal environment remains a key challenge, limiting the ability of NGOs to conduct independent advocacy and engage directly with state institutions. Additionally, the centralised structure of decision-making often delays the implementation of community-driven recommendations. Despite these barriers, the monitoring process underscored the value of local expertise and patient input in shaping effective interventions.



Key Takeaways for Communities

By integrating these lessons, other countries and communities can strengthen their CLM initiatives, ensuring that OAT and harm reduction programmes are accessible, patient-centred, and aligned with human rights standards.

- Communities prioritise tailored methodologies that reflect local contexts and needs, such as focus groups, surveys, or diary-based approaches, which can help uncover nuanced barriers and provide actionable insights while ensuring community ownership of the process.
- They align advocacy efforts with political contexts to engage with decision-makers effectively, building alliances and leveraging evidence to advocate for systemic changes, particularly in restrictive environments.
- The community's primary focus is on community mobilisation alongside data collection. Successful CLM initiatives simultaneously aim to strengthen community engagement and foster collective action to amplify community voices and demand accountability from service providers and policymakers.
- They find balance with external experts' engagement, making sure experts provide support without taking over the process, preserving the independence and authenticity of community-led efforts.
- Doctors would benefit greatly from CLM results if the community ran a consultation with them when putting together a questionnaire or focus group questions, as they have valuable insights arising from their daily routines.
- Communities push for integration of monitoring into national frameworks while safeguarding their independence

by aligning findings with broader health goals and targeting sustainable, systemic improvements in service delivery.

- The preparation stage for an anticipated CCM country meeting appears to offer a more significant window of opportunity for the CLM findings and recommendations than the CCM meeting itself.
- Intersectionality and the core CLM value of various communities representing themselves need to find creative ways to include people with lived experience of OAT and disabilities. Not only did it enhance the credibility of the findings, but it also empowered participants to advocate for their needs. Other communities can replicate this approach by engaging and training community members with intersecting characteristics to lead data collection and advocacy efforts.
- Combining evidence with personal narratives, like semi-structured interviews and personal stories in Georgia and Kazakhstan, adds a human dimension to the data, making the case for reform more compelling; combining can help to connect systemic issues with real-life impacts.
- Funding CLM from the same programme it monitors creates a conflict of interest and undermines its effectiveness. Patient organisations should not be financed directly by the government programmes they are evaluating.
- Another takeaway is that patients and their organisations should focus on fostering positive, regular communication and proactive initiatives with healthcare providers rather than solely criticising healthcare providers.

Sharing EHRA's Experience

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This chapter draws on the role and contributions of the Eurasian Harm Reduction Association in facilitating and supporting CLM efforts.

Since 2017, EHRA sustained progress through supporting and funding CLM with support from the Robert Carr Networks Fund and the Global Fund and championed CLM models and tools, fostering collaboration between grassroots communities and professional researchers. Under this framework, communities identify priority areas for monitoring while researchers provide expertise in navigating the complexities of ethical review processes, data analysis, and other technical requirements. While the model has secured intermittent funding, some of these initiatives already support the comprehensive application of these results, while others continue to communicate patient-owned findings to decision-makers.

In the past three years, EHRA supported efforts to institutionalise CLM and has documented progress across five countries, initially framing the work as a three-year plan aimed at integrating CLM into healthcare systems to enhance the quality of services for people who use drugs. The plan outlined a clear trajectory: by 2022, mechanisms and tools for CLM were to be developed and reviewed across five countries – Georgia, Kazakhstan, Kyrgyzstan, Moldova, and Tajikistan. In 2023, the focus shifted to establishing regulatory frameworks to enable the integration of CLM into healthcare systems. By 2024, the goal was for CLM to become embedded in routine healthcare monitoring, with its findings regularly reviewed at CCM meetings and other healthcare governance platforms and its data informing decisions to improve service quality based on community-driven insights.

The methodological evolution of CLM and capacity building for people who use drugs by EHRA has been pivotal in refining CLM methods in an understandable and easy-to-follow way. EHRA efforts focused on a comprehensive manual on CLM tools developed under the Global Fund's guidance, which proved underutilised; instead, explanatory online interventions were identified as more effective and ensured direct interaction with people who use drugs engaging in CLM. Thus, the manual's complexity necessitated a shift to more accessible formats, including a series of online webinars. These sessions – available online to all interested parties – clearly and accessibly explain key concepts, equipping participants to address advocacy challenges with evidence-based solutions. The end of 2022 was marked with a regional online training on CLM methods, attended by 38 representatives from vulnerable communities across the CEECA region. Participants explored research question formulation, methodology selection, and data collection techniques. The training emphasised practical application, featuring experiences such as the mystery client method in Belarus, which yielded immediate improvements in service compliance



during the monitoring process. Training participants lauded the personalised support provided by EHRA, which extended beyond technical guidance to include ongoing mentorship. This approach fostered confidence among community leaders, enabling them to navigate complex monitoring processes and engage effectively in advocacy efforts.

EHRA's next step was *catalysing change through subgrants*. Building on the training, subgrants were awarded to support CLM initiatives. The call for proposals did not focus exclusively on OAT and suggested a choice of what theme to monitor, and the community choices prioritised this issue, signalling that OAT and access to it remain critical issues for the community and of vital value for people who use drugs. With OAT programmes predominantly state-administered in the region, with rare NGO-led examples limited to Central Europe, CLM efforts sought to address systemic gaps in service delivery and quality. These two factors – being vital and administered by the government services – made monitoring of OAT a top priority for community groups, shaping the whole project on CLM with a unified topic of monitoring the OAT in all five countries. By unifying efforts around OAT, the initiative demonstrated the potential of CLM to drive targeted improvements in healthcare quality and accessibility.

By sustaining *momentum through peer learning and support*, EHRA continued to provide ongoing *supervision* and foster an inclusive and supportive learning environment that has been a cornerstone of its success. Participants consistently highlighted the Association's openness, warmth, and respect for regional and individual challenges. EHRA's resources, coupled with its willingness to provide tailored explanations and additional consultations, empowered participants to overcome self-doubt and actively contribute to CLM efforts. However, challenges and aspirations have been reported, which were discussed in the previous chapters.

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Ryssaldy Demeuova
CCM Secretariat Coordinator,
Kazakhstan

“To advocate effectively, we need access to credible, evidence-based studies on OAT programmes in Russian and English. Without this, resistance to programmes like methadone persists, rooted in misinformation and stigma.”

Feedback from five countries highlights the critical opportunities for which EHRA can provide further support. Interviews with CLM focal points and decision-makers identified specific areas where EHRA's technical support is needed to strengthen advocacy, improve methodologies, and ensure the sustainability of CLM efforts.

- For the CLM initiatives in Georgia, achieving meaningful change needs continued support from EHRA and the Global Fund to establish a dialogue with policymakers to communicate CLM findings and facilitate change. Without this support, the country risks losing the progress made by civil society in working together with people who have used drugs over the past two decades.
- In Moldova, the community's need for technical support is to help establish structured mechanisms to expand ongoing collaboration between the government and all communities doing CLM, not only the community of people who use drugs. This mechanism should ensure mutual benefits by aligning goals and resource sharing.
- In Kazakhstan, there is a need for more in-person training and expert-led workshops, which could enhance the practical skills of the community and expand the reach of CLM efforts. The GF implementers would be interested in training support to enhance primary-level data collection during interactions with OAT beneficiaries and to build CLM capacity for regional and local-level budget practices, adjusting the CLM focus from solely monitoring government agencies and national budgets. Country stakeholders emphasised their need to access credible, evidence-based research databases supporting methadone's effectiveness in HIV prevention; challenges in finding reliable studies in English or Russian slow down advocacy efforts, allowing arguments – such as the claim that methadone is unsuitable for Kazakhstan because it was used in poorer countries – to go unchallenged. User-friendly access to references from reputable journals that can be easily found on Google would be essential to strengthen advocacy with solid evidence.
- Identifying and articulating the voices of women enrolled in OAT's expanding CLM initiatives programme would be very welcome.
- In Kyrgyzstan, doctors are seeking more information about PrEP among people who use drugs, as well as insights into the reasons behind the non-use of extended services at OAT sites.
- In Tajikistan, if there are areas beyond political advocacy that focus on developing services and strengthening the community, it would be important that EHRA ensures these efforts serve the community, going beyond indicators and achievements set by the GF regional project. Avoiding short-term actions aimed at quick wins when addressing long-standing issues in OAT requires sustained, strategic efforts.

Valentina Mankieva

AMAL Central Asian Women's
Network, Kazakhstan

“CLM is now truly under the community's control, with EHRA encouraging adaptation to our local contexts – a consistently valuable approach. Kazakhstan has made progress with OAT monitoring, but we must push further. With more resources and in-person support from EHRA experts, standing together as a stronger team, our conclusions and presentations can resonate on a whole different level.”

As CLM becomes increasingly embedded in healthcare systems, strengthening in GF requests, for instance, in Kazakhstan and Tajikistan, more sustained efforts are expected from EHRA and other networks that communities and experts will continue collaborative efforts and will be able to shape a more equitable and responsive approach to service delivery. Furthermore, the integration of CLM into healthcare systems remains an ongoing process, requiring sustained advocacy and resources. Participants underscored the value of sharing experiences across countries, such as the reporting practices of Ukraine, Georgia, and Moldova, to refine approaches and amplify impact. While significant progress was reported – mechanisms and tools were developed, regulatory documents were prepared, and CLM reports were an influential source for discussions in CCM meetings – broader contextual challenges hindered the full realisation of the complete vision of this initiative. These challenges, all beyond the implementers’ influence, included shifting political landscapes, new regulatory barriers, and systemic inertia in certain contexts. Despite these obstacles, the initiative’s achievements demonstrate the potential of CLM to drive meaningful change, even as broader systemic factors require sustained advocacy and long-term engagement to address. The lessons learnt through this initiative underscore the transformative potential of CLM to mobilise communities, inform policies, improve services, and strengthen advocacy across diverse contexts.



Recommendations

Now, when this overview of the EHRA three-year initiative on CLM is completed, the conclusions highlight the critical role of strategies for strengthening collaboration between community organisations and decision-makers. It is appropriate that they emphasise the importance of integrating CLM findings into policy and programme development. The experience in five countries offers relatively low-cost, scalable CLM processes that are easy to implement and allow continued data collection and advocacy with limited resources. Below, this report seeks to capitalise on the insights gained through CLM and foster long-term improvements in OAT services. CLM findings demonstrate the need for sustained advocacy to align policies with human rights principles, emphasising the socio-economic benefits of inclusive and non-punitive approaches.

The recommendations revolve around ensuring the sustainability of CLM through diversified funding and institutional support and establishing structured mechanisms based on win-win principles. It is a work in progress toward fully integrating CLM efforts into national frameworks. The continuation requires patience, flexibility, and a commitment to context-sensitive approaches from donors, communities, and policymakers.

To Donors:

- Allocate sufficient resources for community organisations to continue CLM efforts; explicitly fund advocacy efforts to ensure that CLM data inform policy change.
Donors must ensure that community-led monitoring truly reflects the priorities and needs of the community rather than serving donor-driven agendas.
- Foster dialogue between the community of people who use drugs and policymakers, especially from the Ministry of Health, through CCMs and other public health forums addressing structural

barriers to community participation and service delivery.

- Ensure greater flexibility and increased funding for CLM as essentials. Community groups might require more time and resources to understand and adapt methodologies, collect and analyse data, and engage in effective advocacy than those in calendar plans, especially those made without explicitly consulting community groups.
- Ensure that community-led monitoring is independent in its funds, agenda, and implementation. External experts can provide every technical assistance from reviewing questionnaires to suggesting data interpretation, but the balance of power must remain with the community.
- Donors and grant implementers should plan for sustained training to enhance the community's skills in CLM, moving beyond one-off webinars to hands-on mentoring. Financial management support and simplified reporting effectively empower grassroots organisations of people who use drugs. This, in turn, ensures that CLM findings are robust, credible, applicable, and effectively communicated to policymakers.

To Policymakers:

- Recognise the critical role of community-led monitoring in achieving OAT or other treatment programme targets. The community input, expertise, and knowledge can get a sign behind the figures, improve treatment outcomes, and ensure programme accountability.
- Establish structured mechanisms for ongoing community collaboration, ensuring mutual benefits by aligning goals, sharing resources, and fostering trust. This approach will enhance the effectiveness of

- funding spending, improve the quality of OAT services, ensure inclusivity and accountability, and help achieve or correct indicators and goals of HIV and drug addiction treatment programming.

To Community Groups:

- Focus on achievable monitoring goals that address immediate patient needs and programme gaps.
- Prepare for future advocacy opportunities and stay creative as conditions evolve, even in restrictive political environments.
- Where possible, take a more active role by using social media, joining initiatives that increase visibility, and presenting as a strong citizen voice.
- Continue to collaborate regularly with doctors, service providers, government agencies, and international organisations to communicate your CLM findings. Collaboration is shown to be more effective when it focuses on solutions, not just problems.

- Prioritise the well-being of CLM staff and volunteers and include basic support mechanisms and fair pay into your funding requests, ensuring sustainability and resilience in your work.

- Continue to look for diverse funding sources to prevent CLM efforts from becoming sporadic and fragmented; this will also help you remain independent in your opinions.

- When resources are limited, personal stories, patient narratives, and simple findings from your CLM are potent tools for advocacy and fostering understanding among stakeholders. They are enough to tell about your community experience.



Annex 1. Interview guides

CLM Individual Interview Guides

Interview Guide for Community Representatives

Background and Objectives of CLM

Can you describe the main objectives of the CLM project in your country?
What motivated your organisation to monitor the OAT programme specifically?
How do you see the role of CLM in influencing OAT services and policies?

Implementation of CLM

Why did you want to launch the CLM initiative?
What method of CLM did you choose and why?
How did the roll-out of CLM go?
How did the data processing go?
How were the findings documented and analysed?
Did you receive what you were looking for because of your data collection?
Would you choose this monitoring method again?
Can you share the challenges during the CLM implementation?
Were there any partnerships or collaborations that helped and how?

Advocacy

What findings were documented?
Can you describe any advocacy efforts made based on the data collected?
What role did national decision-makers and other stakeholders play in your advocacy?
To what extent were national and local stakeholders supportive of your CLM efforts?

Key Findings and Results

What are the key findings from your CLM?
Have there been any notable impacts or changes in OAT services because of the CLM?
How did stakeholders react to your findings?
How has the CLM influenced or shaped national policies or practices on OAT?

Challenges and Lessons Learnt

What were the challenges for your CLM? How did you overcome these?
Were there any barriers to engaging with policymakers or service providers?
Are there any valuable lessons learnt for other countries or communities?

Recommendations

What recommendations would you provide for CLM?

Support

How could the government better support and fund CLM in your country?
How did EHRA support your organisation during the project?
How could EHRA better support you in the future?

Interview Guide for Policymakers

The interview guide is structured to gain a policymaker's insights on the impact and value of CLM in influencing OAT policy and service improvements, as well as potential areas for collaboration and policy advancement.

Role and Perspective on OAT and CLM

How would you describe your role in the opioid agonist treatment (OAT) programme?

What is your understanding of community-led monitoring (CLM) and its role in improving OAT services?

Awareness and Involvement in CLM Initiatives

Are you aware of the recent CLM initiatives undertaken by community organisations to monitor OAT?

How frequently do you or your office engage with community organisations involved in CLM? Can you share any specific examples?

Have you reviewed any findings or recommendations from the CLM project?

If yes, what are your thoughts on the findings? How do they align with the government's observations or priorities?

Did CLM data contribute to decision-making processes on OAT policies?

Have any actions been taken (or planned) based on these findings?

In what ways do you think community insights can be better integrated into OAT planning and policy development?

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Key Challenges and Opportunities

What are the main challenges or barriers to improving OAT services in our country? Can CLM help address these?

Are there challenges in working with community organisations or incorporating their data?

What further actions could policymakers take to support and strengthen CLM initiatives?

Are there any recommendations you would make?

Annex 2.

EHRA CLM

Resources

[*The Position of Regional Networks on Community-Led Monitoring \(CLM\)*](#) outlines the results of a regional consultation in Istanbul, Turkey, in 2023, that brought together diverse regional community networks and organisations to establish a shared vision for CLM in CEECA. The document defines CLM as a community-driven process aimed at addressing issues affecting quality of life, including services, human rights, and health policies. It emphasises core principles such as community ownership, independence, and advocacy integration. The position paper also addresses managing conflicts of interest, ensuring CLM sustainability through adequate funding and capacity building, and fostering collaboration among community organisations, governments, donors, and global partners. Key recommendations include prioritising community leadership, creating sustainable funding mechanisms, and integrating CLM data into decision-making and advocacy processes to strengthen community systems and improve service delivery.

[*This link*](#) highlights in more detail the results of CLM initiatives and OAT programmes in five countries from this report: Kazakhstan, Kyrgyzstan, Moldova, Georgia, and Tajikistan, facilitated by the EHRA. This initiative, in more detail described in this report, focuses on assessing the effectiveness, accessibility, and quality of OAT programmes through community-led monitoring (CLM). The project emphasises the critical role of people who use drugs in evaluating services, addressing barriers, and advocating for improvements. Key activities included data collection, stakeholder engagement, and evidence-based advocacy to ensure that OAT programmes meet community needs and align with human rights principles. The page provides an overview of the initiative's objectives, methodology, and outcomes, showcasing EHRA's commitment to inclusive, community-driven approaches to improving services for people who use drugs in the region.

The [*Community-led Monitoring Resource Page*](#) provides an overview of the CLM efforts supported by EHRA in the Central and Eastern Europe and Central Asia (CEECA) region. The page overviews key principles of CLM, including community ownership, independence, and the use of collected data for advocacy and decision-making, and emphasises the role of CLM in addressing systemic issues, ensuring accountability, and strengthening community systems.

The compendium [*Practical Handbook on Community-Led Monitoring Tools \(EHRA, 2022\)*](#) serves as a step-by-step guide for communities to implement CLM effectively. The handbook provides practical tools, methodologies, and case studies tailored to support community-led networks in monitoring services, identifying barriers, and advocating for improvements. It emphasises the importance of community ownership, data-driven decision-making, and sustainable practices in improving health and social services. The handbook aims to empower communities to take an active role in enhancing the quality, accessibility, and accountability of services and serves as a must-have guide every activist should keep within reach.

[*CLM Tool for Methodology Selection*](#) provides a comprehensive guide to systematically collect, analyse, and use data to improve harm reduction services. Packed with practical solutions, it offers clear options for gathering and organising information to break down barriers and expand access to healthcare and social support systems. Featuring step-by-step instructions, best practices, and real-world case studies, this tool empowers you to lead effective monitoring and advocacy efforts that deliver tangible results.

[*CLM Community of Practice*](#), facilitated by EHRA, serves as a collaborative platform for community-led networks, civil society organisations, and technical partners. It aims to enhance the effectiveness of CLM initiatives by fostering the exchange of knowledge, experiences, and best practices. Through webinars and meetings, participants share insights and strategies to improve health services and advocate for the rights and well-being of people who use psychoactive substances in the CEECA region. The page includes links to four webinars, providing valuable resources on key topics related to CLM and offering participants practical tools and actionable insights to strengthen their advocacy and monitoring efforts.

Another related publication, [*“Associated Trio”: Accelerating the Accession of Georgia, Moldova, and Ukraine to the EU. Criminal Drug Law and Policy Dimension*](#) by M. Golichenko (2024), examines the role of criminal drug laws and policies in the European Union accession process for Georgia, Moldova, and Ukraine, three countries where the CLM community projects from this report were based. It highlights the alignment of these countries' drug policies with EU standards as a critical factor in their integration, including the role of CLM. The report assesses current legal frameworks, identifies barriers to compliance, and provides recommendations for reforms needed to harmonise with EU norms.



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