

COMMUNITY-LED MONITORING OF OPIOID AGONIST TREATMENT

Including
WHO quality
of life indicators
(based on EHRA
methodology)

This document is a publication of the Eurasian Harm Reduction Association (EHRA). EHRA is a non-profit, membership-based public organisation that unites and supports harm reduction activists and organisations in Central and Eastern Europe and Central Asia (CEECA). EHRA's mission is to actively unite and support communities and civil society to ensure the rights and freedoms, health and well-being of people who use psychoactive substances in the Central and Eastern European and Central Asian region.

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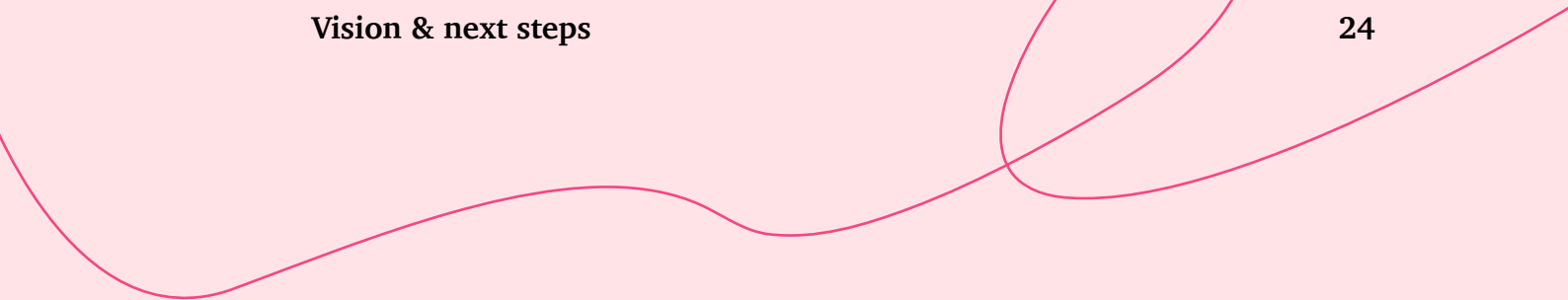
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ACRONYMS

ART

Antiretroviral
Therapy

CCM

Country
Coordinating
Mechanism

CEECA

Central and
Eastern Europe
and Central Asia

COVID

Coronavirus
Disease

EHRA

Antiretroviral
Therapy

HCV

Hepatitis C Virus

M&E

Monitoring and
Evaluation

MoH

Ministry of Health

NGO

Non-
Governmental
Organisation

OAT

Opioid Agonist
Treatment

QoL

Quality of Life

RCF

Robert Carr Civil
Society Networks
Fund

SRDC

Non-Support,
Research and
Development
Centre (Ukraine)

TB

Tuberculosis

UNFPA

United Nations
Population Fund,
formerly the United
Nations Fund for
Population Activities

UNODC

United Nations
Office on Drugs
and Crime

VOLNA

Ukrainian
Network of People
who use Drugs

VOT

Video Observed
Therapy

WHO

World Health
Organization

I. SUMMARY

Community-led monitoring (CLM) is a globally recognised tool that provides valuable insights into the quality and accessibility of provided services, as well as health and well-being outcomes. The Eurasian Harm Reduction Association (EHRA) has supported the development of CLM methodology to assess client satisfaction and quality of life (QOL) in Opioid Agonist Treatment (OAT) programmes. This approach was piloted in Ukraine and subsequently implemented in Belarus, Estonia, Georgia, Montenegro, and the Republic of Moldova. The research generated new knowledge about OAT programming and empowered communities to advocate for improved services.

The Central and Eastern European and Central Asian (CEECA) region faces challenges related to low access to harm reduction services and poor OAT service quality. The World Health Organization (WHO) recommends a minimum of 20% coverage of people who inject opioids with OAT, a threshold unmet in many CEECA countries. Transition to state funding of OAT programmes and cost-cutting efforts have negatively affected the provision of psychosocial support as part of such OAT programmes.



The following are the main findings of the research conducted in the six countries involving 2,113 participants:

Paradox of satisfaction

In Belarus, Georgia, and Ukraine, respondents expressed high satisfaction with the OAT programme overall, but low satisfaction with specific services or their own health. This suggests a perception that OAT is primarily about the dispensing of medication rather than a comprehensive set of services.

Psychological support

Respondents across all the countries reported high levels of psychological distress, anxiety, depression and the need for more support, including medication.

Availability and satisfaction with social services varied, with some countries facing significant shortcomings. Staff played a crucial role in treatment outcomes, but programmes were generally understaffed.

Health and medical services

Respondents generally had a negative evaluation of their own health. Estonia had the highest level of satisfaction with healthcare received at OAT services, whilst Belarus had the lowest level.

Employment

Unemployment was a prevalent issue for respondents in all countries, impacting their quality of life. OAT programme policies and practices often hindered access to, and retention in, employment.

Safety and confidentiality

Feelings of safety and confidentiality of respondents varied, with some expressing concerns about data security. Inadequate premises for confidential counselling sessions with OAT centre staff is common in each of the countries.

Prison

Imprisonment was a significant challenge faced by programme participants in all countries.

The CLM initiative led to policy changes in Ukraine, Georgia, Montenegro, and Moldova. For instance, in Ukraine, the research revealed gaps in psychological and social support within the OAT programme, prompting advocacy efforts to address these deficiencies. In Georgia, the findings influenced decisions on take-home dosing, while in Moldova, they sparked a formal investigation into programme outcomes. Additionally, the research led to increased access to buprenorphine in Moldova and improved staffing at a central clinic in Montenegro.

Furthermore, CLM enhanced the capabilities of community organisations by providing them with new research skills and in establishing partnerships with professional researchers. Getting approval from ethics committees added credibility to the community organisations, allowing them to engage with institutions and to strengthen their advocacy. This initiative also boosted the confidence of communities and helped them fine-tune their advocacy goals. Overall, CLM not only generated crucial knowledge about OAT programmes but also transformed community organisations, enabling them to play a more influential role in advocating for positive changes in policy and practice.

Based on the findings, the following recommendations are proposed:

- 1. Quality of life and client satisfaction should be frequently and routinely monitored** as part of the M&E approach to OAT programming.
- 2. Community-led monitoring should be leveraged** for the monitoring and evaluation of OAT programmes as such enabling collaboration with communities allows are more informed understanding on how best to improve quality of life and client satisfaction.
- 3. Referral systems should be strengthened** between OAT programmes and HIV, hepatitis C virus (HCV), and tuberculosis (TB) related prevention, testing, treatment and support programmes.
- 4. Psychosocial support** provided at OAT sites should be enhanced.
- 5. OAT service hours should be adjusted** to enable OAT participants to more easily pursue employment.
- 6. Individual approaches** to take-home doses **should be enabled**.
- 7. Decriminalisation would reduce imprisonment** of OAT clients and until decriminalisation is instituted, continuity of access to OAT programming should be guaranteed for people experiencing detention.
- 8. Quality of life and client satisfaction studies can be leveraged** to counter efforts to cut costs, or to “optimise” spending, which would otherwise push for the elimination of psychosocial support as a service that is too costly.

II. INTRODUCTION

Community-led monitoring (CLM) is acknowledged globally, and in the Central and Eastern European and Central Asian (CEECA) region it has revealed new unique knowledge that can help communities, service providers and policymakers to make decisions that improve health and wellbeing outcomes. In 2019, EHRA took on the task to develop and pilot a CLM approach for client satisfaction and quality of life (QOL). Piloted initially in Ukraine, the approach was rolled out in Belarus, Estonia, Georgia, Montenegro and the Republic of Moldova. The research produced valuable new knowledge about OAT programming and ways that it might improve. Both the process and product of the research empowered communities to advocate for changes to improve outcomes for people who use opioids. This document provides an overview of the new knowledge generated by the research as well as analysis of how the process of carrying out the research affected the communities involved in it, and how the knowledge was used by communities and their partners to advocate for change.



III. BACKGROUND

The CEECA region is home to many countries with high rates of harm from opioid use, linked with low levels of access to harm reduction programming and harmful drug policy¹, where opioid agonist therapy (OAT) is an important measure for improving health and wellbeing of people who use opioids. Coverage of OAT services varies by country but is less than 20% of people who inject opioids in all countries of the region except for Croatia, Estonia, Hungary, Montenegro, North Macedonia and Slovenia². In Ukraine, for example, of an estimated 346,000 people who inject drugs, only 11,853 (3.5%) access OAT services³, and in the Republic of Moldova, only 522 people are OAT clients even though 19,300 people are eligible⁴. WHO recommends that a minimum of 20% of people who inject opioids should have access to OAT to prevent the transmission of communicable diseases, including HIV⁵.

OAT services in the region are often of poor quality and not based on client-centred or gender sensitive approaches. As countries of the region have transitioned to funding OAT services with state funding rather than from Global Fund grants, efforts to cut costs and to 'optimise' programming has often led to reductions in psychosocial support and training for healthcare workers is increasingly neglected.

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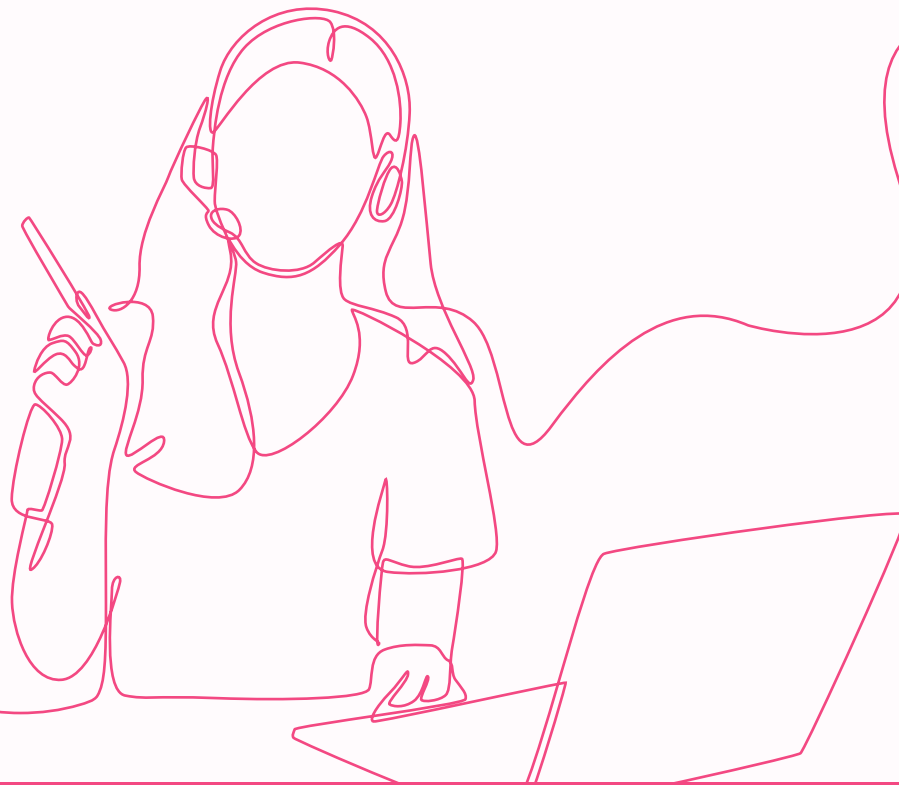
most often focused on coverage and infectious disease-related outcomes to measure programme effectiveness. They do not systematically measure client satisfaction, nor the impact the programme has on quality of life. Therefore, in many cases, existing approaches to monitoring and evaluation may be missing indicators that could inform the improvement of quality.

For acute conditions, performance indicators are useful to measure the elimination of disease or its symptoms. But for chronic diseases, a more nuanced approach is needed. Since drug dependence is a chronic condition, measuring client expectations, satisfaction, and quality of life can give greater

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insights into how programmes are impacting client health and wellbeing and can better inform how programme quality can be improved. The assessment of QoL and client satisfaction can also inform as to how programme coverage can be improved since client satisfaction is linked with adherence.

Given the degree to which research on client satisfaction and QoL of OAT clients is limited, EHRA set out to develop and pilot an approach to assessing OAT programmes that incorporates assessment of QoL and client satisfaction undertaken in line with a community-led monitoring approach. EHRA has a long history of supporting work to enable the voices of people who use drugs to be heard and to be influential in the making of drug-related policy.



BOX 1: DEFINITION OF COMMUNITY-LED MONITORING⁷

“ *The monitoring of issues, phenomena and processes important to the community that is carried out by the community and led by the community on an ongoing basis until the desired result is achieved, and in which the fundamental principles of CLM are observed. The data obtained through CLM is used as the basis for decision-making in order to achieve positive changes for the community.*”

EHRA developed an cooperative approach which paired community-led groups of people who use drugs with academic researchers to carry out research with the approval of the Ethics Board of the respective country. The approach was first piloted in Ukraine and, subsequently, research based on the model developed in Ukraine was used in Belarus, Estonia, Georgia, Montenegro and the Republic of Moldova.

IV. METHODOLOGY

There are few instruments to measure the level of satisfaction of OAT clients. Hence, in 2019, EHRA set out with partners in Ukraine to develop a new model based on the principles of CLM. A research instrument was developed and research was conducted by the Support, Research and Development Centre (SRDC) in partnership with the Ukrainian Network of People who use Drugs (VOLNA), Drug-users Ukraine, a Drop-in Centre, ENAY and EHRA (within its Robert Carr Civil Society Networks Fund (RCF) as part of a project entitled, 'Thinking Outside the box: Overcoming the Challenges in Community Advocacy for Sustainable and High Quality HIV Services', implemented by the Eurasian Regional Consortium with support of UNFPA.

The community of people who use drugs were involved in all stages of the research, including the process of developing the study design and protocol and in carrying out the research and analysis. As stated in the report documenting Ukraine's experience,

“ It is important to understand that all major agreements between researchers, the community and its members will be made during the writing, approval and amendment of the protocol...the community and the research team may not necessarily share the same views and opinions on all issues. Accordingly, the community may have knowledge of what is going on in the field, while the researchers or consultants offer their own expertise based on research experience, previous work conducted in the field or experience with the topic of study.”⁸

BOX 2: CLM PRINCIPLES

- **CLM is initiated and implemented by the community, the data obtained belongs to the community and are used to bring about changes;**
- **The community leads CLM at all stages, including the stage of CLM priority setting, methodology development, monitoring process implementation, data interpretation and further advocacy;**
- **CLM can be implemented independently of funding sources, and the monitoring process and subsequent use of results must be independent;**
- **Further advocacy steps are an integral part of the CLM process;**
- **Any data collection tools can be used to implement CLM;**
- **CLM plays an important role in building capacity and in strengthening community systems;**
- **CLM is implemented by the community directly impacted by the issue(s) being monitored;**
- **The independence and safety of community representatives is ensured at all stages of CLM;**
- **There is no, or minimal, conflict of interest in CLM;**
- **When CLM is conducted by regional community networks, the involvement of representatives of the local communities is mandatory;**
- **CLM can be permanent, periodic or one-time;**
- **The analytical data obtained through CLM must be publicly available;**
- **Security and storage of raw data (both offline and online) must be ensured in CLM.**

The study design involved both qualitative and quantitative methods. An initial smaller scale qualitative research (semi-structured interviews of service providers and OAT clients) was conducted to help define classifications for larger scale quantitative research. For the quantitative research, a number of respondents was determined which would be conducive to finding statistically significant results¹.

Researchers and community representatives worked together to develop a study design and protocol. The principles of CLM (*see Box 2*) were adhered to throughout the process. The protocol was then submitted to the Ethics Review Board. When the qualitative research was undertaken using semi-structured interviews of service providers and clients, the researchers and community representatives discussed its implications for the larger quantitative study. The protocol was revised and again submitted to the Ethics Review Board before the quantitative part of the study was undertaken.

Those involved in data collection were trained in the methodology and on how to obtain informed consent. Respondents (to interviews and the quantitative surveys) had the risks and benefits of participating in the research explained to them and given an opportunity to sign an informed consent statement. Respondents were given an incentive to participate in the research.

The research was designed to provide information in 3 basic information blocks:

- 1. Basic demographic information;**
- 2. Questions pertaining to quality of life, addressing it in 4 domains (*see Box 3*): physical health, psychological aspects, social relationships, and environment; and,**
- 3. Client satisfaction, including physical setting, quality of care, and quality of psychosocial support.**

¹ Statistical significance is a determination that a relationship between two or more variables is caused by something other than chance. <https://www.investopedia.com/>

BOX 3: DOMAINS OF QUALITY OF LIFE



Physical health (activities of daily living; dependence on medicinal substances and aids; energy and fatigue; mobility; pain and discomfort; sleep and rest; and work capacity);



Psychological aspects of functioning (body image and appearance; negative feelings; positive feelings; self-esteem; spirituality / religion / personal beliefs; thinking, learning, memory and concentration);



Social relationships (personal relationship; social support; and sexual activity); and,



Environment (opportunities to acquire new information and skills; opportunities for recreation / leisure time activities and participation in them; physical environment (air pollution / noise / traffic / climate); and transportation).

When the research in Ukraine was completed, EHRA — with the help of the Ukrainian team — developed a methodology for use in other countries. The methodology suggested questions that could be used in all countries but also made space for the questions and approach to be adapted to the needs of each country. The publication is entitled, ‘Methodology Assessment of Client Satisfaction with OAT Services’.



V. THE UNIQUE IMPACT OF COMMUNITY-LED MONITORING

This community-led monitoring programme not only produced new knowledge about OAT programmes but, carried out in line with the principles of CLM, it also strengthened the capacity of communities, gave them new partnerships, helped their voices be heard, gave credibility to their messages and, ultimately, had



Communities were in the lead at all stages of the research, from forming research priorities, developing and revising research methodologies, gathering data, interpreting the data and ultimately using it in their advocacy work. This type of involvement meant that the process had an impact on communities and it also strengthened the potential for communities to have an impact on the policies that affect them.

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COMMUNITY-LED MONITORING IMPACTING POLICY

The CLM work contributed to important incremental progress towards policy changes in Ukraine, Georgia, Montenegro and the Republic of Moldova. Once the research was completed, EHRA offered mini grants to the community groups that had been leading the research to support follow-up advocacy activities. The application process for such grants was designed to support advocacy planning.

RESISTING BUDGET CUTS IN UKRAINE

In Ukraine, the study concluded that although the OAT programme was in accordance with official Decree No. 200, it should provide medical, social and (as applicable) psychological care and support but there are immense gaps in the provision of psychological care and social support. The authors noted that, “*WHO defines health, ‘as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ and call on community and civil society, ‘to request to guarantee the full realisation of the right to health instead of just providing improved access to treatment’.*” The Ukrainian Network of People who use Drugs (VOLNA), which had been a leading partner in the research initiative together with its partners, took on the work of calling for these gaps to be filled. EHRA provided them with a mini-grant to support their advocacy work.

VOLNA was established in 2018 with goals involving the monitoring of the government’s commitment to provide and scale-up the OAT programme in the midst of ongoing transition from sourcing funding for the OAT programme with international funds to funding them fully from state resources. 2018 was the first year when OAT medicines were fully funded by the state. Transition to funding services from state resources has taken place at a slower pace. VOLNA, together with its partners, have actively advocated for the scale-up of funding for services. During the process of preparing its most recent funding request (for funds for the years 2024-2026), VOLNA was actively engaged in resisting forces that were calling for approaches to ‘optimise’ costs by slashing funding for psychosocial services.

Empowered by the experience of the research, and equipped with its evidence, VOLNA and its partners — Drug-users Ukraine, a Drop-in Centre and ENEY — were able to push for inclusion of psychosocial support services in the funding request.

“The research”, said Oleg Dimaretski, Head of VOLNA, “helped us articulate our case. And the fact that it was state sanctioned gave it more weight.”

TAKE HOME DOSES INCLUDED IN A NEW DRAFT OAT REGULATION

In Georgia, the community-based organisation, Rubiconi, which operates with a mission to support the right for health and basic/constitutional rights of people with drug use dependence, presented the findings of the study to their Country Coordinating Mechanism (CCM) and their Ministry of Health (MoH), with the findings subsequently often cited in deliberations. The study recommended an individual approach be taken to dosing and take-home dosing – allowing it when desired by, and positive for, the wellbeing of clients. During the COVID-19 pandemic, take-home doses were allowed. Although some clients found psychological comfort in daily visits, enabling take-home doses is appreciated for its convenience by programme participants. The study helped Rubiconi envision the promotion of access to take-home dosing as its advocacy objective. They also produced diaries of OAT programme clients to back-up the quantitative research with stories from peoples’ lives about how the policy affected them. Using such knowledge generated by the study, Rubiconi and its partners argued that take-home dosing will lead to better outcomes for programme participants and would ease the workload of medics. This work had an impact on the content of a new regulation on OAT which is currently awaiting approval in that it would enable the expansion of take-home dosing.

INSPIRING A FORMAL INVESTIGATION INTO OAT PROGRAMME OUTCOMES IN THE REPUBLIC OF MOLDOVA

In Moldova, the drug user community-led organisation, PULS Comunitar, took its advocacy work to a whole new level as a result of the CLM programme. PULS Comunitar knew that the OAT programme was not achieving its objectives because the participants were not getting the support services that they needed. Testing this hypothesis was established as one of the goals of the research programme. The research did not disappoint — it proved that their hypothesis was true and fleshed it out with scientific detail.

PULS Comunitar presented the findings to the CCM working groups but they understood that they needed to take it further as it was often the case that the CCM did not make changes in reaction to problems raised in its forums.

PULS Comunitar decided to present their findings to Parliament. They became members of the Parliamentary Platform on Reform of Drug Policy and presented their findings. They showed how the lack of psychosocial support services was impacting client health and wellbeing. They showed that there was no formal



Their findings, as well as the findings presented by UNODC, contributed to the decision by the Parliamentary Platform to launch a formal evaluation of services for people who use drugs, including the OAT programme, and its outcomes.

M&E approach that provided the information needed to answer questions about whether money spent on the programme was helping to achieve the goals set before them. They showed that there was a lack of coordination between different services, such as between services designed to help people with employment and the OAT programme. They raised complex issues, like the fact that take-home dosing improved client wellbeing but many

services were reluctant to implement it because they were allocated funds based on the number of client visits (and visits are more frequent when take-homes are not allowed). Their findings, as well as the findings presented by UNODC, contributed to the decision by the Parliamentary Platform to launch a formal evaluation of services for people who use drugs, including the OAT programme, and its outcomes.

INCREASING ACCESS TO BUPRENORPHINE IN THE REPUBLIC OF MOLDOVA

The research showed that buprenorphine was offered in only 20% of sites. Hence, PULS Comunitar set out to advocate for increased access to buprenorphine. They wrote to the MoH asking them to create a Working Group focused on the OAT programme to discuss issues like inadequate access to buprenorphine and problems related to the inconsistent supply of medicines. Medics had reduced doses of OAT medicines in order to avoid stock-outs that were expected due to problems with procurement. MoH issued an order to create the Working Group which became a forum where partners from the narcological service, the community and international partners could work together to solve problems. PULS Comunitar presented their research findings showing inadequate access to buprenorphine which had led to dose reductions. The Republican Narcological Department took action on the issue and now as many as 60% of sites offer buprenorphine.

INCREASED STAFFING AT A CENTRAL CLINIC IN MONTENEGRO AND NEW STRATEGIC DIRECTIONS

The research undertaken in Montenegro showed, as it did in other countries, that access to psychosocial support for OAT participants was inadequate. A key conclusion of the report was that overburdening of their larger more central sites had a negative impact on client satisfaction. In those central sites, staffing was inadequate to address the psychosocial needs of their clients. Only 6% of participants had used the services of a social worker, though as many as 70.8% said they would use it if it were available. The authors recommended that the capacity of OAT centres be built to enable greater access to psychosocial

support for OAT clients. Their data showed that centres with better staff-to-client ratios performed better. The NGO's Juventas and Link used this comparative data in their advocacy efforts and found it to be particularly convincing. They presented their results to the managers of all of the OAT sites and to the MoH. As a result of their efforts, a central clinic added more psychiatrists and more medical staff to its roster.

In the process of carrying out the research, it also became clear that the government did not have a system for tracking

data about the programme or mechanisms for monitoring and evaluating the quality of the OAT programme which would be necessary in order to make strategic decisions about how to improve the programme. MoH appreciated the information that Juventas and Link provided and enabled their involvement in the creation of Montenegro's new Strategy on Drugs. MoH heeded their recommendations and is in the process of conducting a mapping of OAT sites and addressing the need to create a new Management Information System for the OAT programme.



MoH appreciated the information that Juventas and Link provided and enabled their involvement in the creation of Montenegro's new Strategy on Drugs. MoH heeded their recommendations and is in the process of conducting a mapping of OAT sites and addressing the need to create a new Management Information System for the OAT programme.

COMMUNITY-LED MONITORING STRENGTHENING COMMUNITIES

The CLM initiative not only contributed to policy change but also contributed to profound changes within the community organisations that were leading it. For all of the community groups involved, it was their first time to conduct official research. While some had conducted research before, they had never

done it in partnership with a professional research team and they had never done it with official government endorsement through their national Ethics Committee. The exercise gave them new skills, new partnerships, a new level of credibility and with it a new sense of pride and a refined vision of their advocacy objectives. All of this came, of course, in addition to new knowledge and proof of the needs of their community.

The approach that EHRA enabled has allowed communities to lead in formulating the goals of the research.

“We were able to establish goals of research in line with our assumptions and priorities,” said Vitaly Rabinchuk from PULS Comunitar in Moldova. “We saw that our opinions had weight”, said Zaza Karchkhadze of Rubikoni in Georgia.

In all of the countries, the unique knowledge that communities have of their own needs and priorities was leveraged to focus the research on issues that they prioritised. This also ensured that the research would produce knowledge that the communities could use in their advocacy work.

NEW SKILLS

For all of the community organisations involved, this was their first time working on research of this type. *“Of course, we had done research before but never with this kind of scientific rigor, never with Ethics Committee approval,” said Oleg Dymaretski from VOLNA in Ukraine.* The organisations all learned about the phases and principles of research. They learned how to apply to their respective national Ethics Committee for approval. They learned how to leverage that approval for access to institutions during the research. They also learned how to cite their results as proof. EHRA provided them with skills building exercises and tools along the way as well as opportunities for them to learn from each other. Communities in Georgia received help from communities in Ukraine and communities in Montenegro looked to Georgia for inspiration.

PARTNERSHIP AND COOPERATION

The organisations also learned how to cooperate with a new kind of partner. *“We learned to hire experts that had knowledge that we didn’t have”, said Vytalij Rabinchuk at a PULS community centre.* None of the organisations had partnered with professional researchers before. Some of the partnerships built

during the exercise are expected to last. *This was the first time we cooperated*”, Oleg Dymaretski said of his partners from ENEY, “and we keep in touch and it is helping with referral.”

CREDEBILITY

The fact that the research was undertaken with rigor and with ethics committee approval gave both the information and the community organisations using it a new level of credibility. Firstly, this credibility gave the organisations access to institutions during the research that they otherwise would not have been able to access. *“Some of the OAT sites were reluctant to participate while others were friendly and when they were reluctant we showed them the ethics committee approval and they let us work at their sites”*, said Elena Antonova of LUNEST in Estonia, highlighting also that they were able to work with prisons for the first time. She noted that the process of getting ethics committee approval was an “autocratic nightmare, but worth it”.

The community groups appreciated that the research results would be seen as more authoritative than more casually conducted surveys.

“We won’t just be screaming — we’ll have proper research to back up our demands”, said Elena Antonova of LUNEST in Estonia. *“Now we can prove what we knew — when you are prepared, you can make the argument”*, said Ivana Vojvodic and Marija Mijovic of Juventas and LINK, respectively, in Montenegro.

In Moldova, Vytalij Rabinchuk of PULS Comunitar highlighted that the exercise has had a profound impact on how they were seen by officials in their country, saying, “they looked at us like equal partners”. He noted that the process helped them to look for solutions. *“We were used to being seen as those always looking for who was at fault, but now we were proposing solutions. They appreciated it when they saw that one of our central recommendations was that their staff be expanded. There were advantages for all in the solutions we were proposing”*. Vytalij added, *“the response that we got was different from before — we were thanked — they actively invited us to meetings. They looked at us as equal partners”*.

PRIDE

An achievement of the CLM work — the importance of which cannot be underestimated — is that it gave the communities a newfound sense of

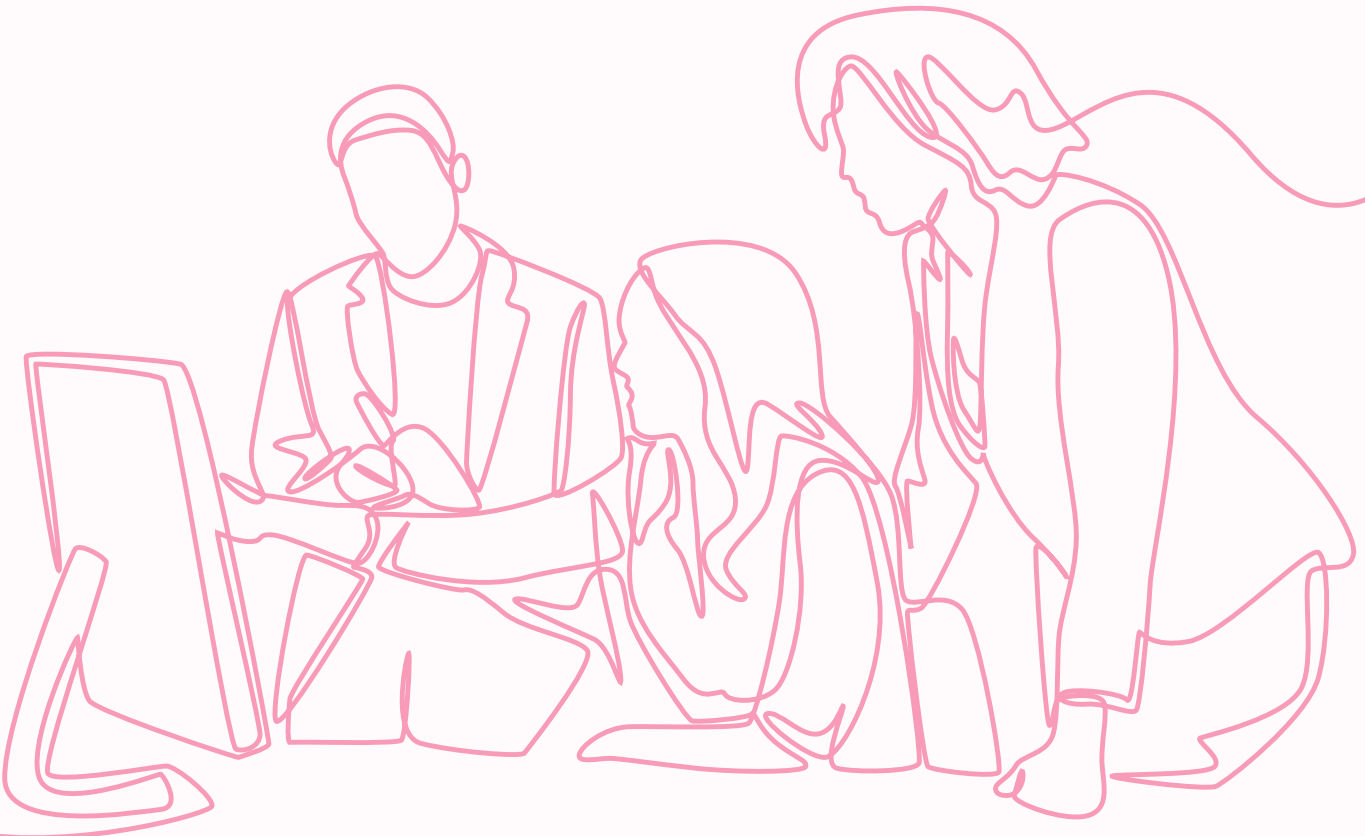
pride, something particularly important for communities faced with stigma, discrimination and criminalisation.

“As a leader of a community led organisation, I am proud that we are doing this”, said Elena Antonova of LUNEST in Estonia. Of her volunteers, she said, “they were fearful and now they are brave. They did a lot of work for free because they believed in it”. Zaza Karchkhadze of Rubikoni in Georgia said, “it gave us a sense of pride”.

VISION & NEXT STEPS

The process and results of the research helped communities refine their vision and their specific advocacy goals.

“It strengthened us as a network — helped us find our priority issue and focus on it”, said Zaza Karchkhadze of Rubikoni in Georgia. Vytalij Rabinchuk of the PULS community centre also commented that, “It gave us a more concrete vision of next steps; it helped us to look for solutions, not just highlight problems”.



VI. TENDENCIES AND CONTRASTS IN OAT PROGRAMMING IN THE COUNTRIES

In each of the 6 countries, research was conducted in accordance with the methodology described above. A total of 2,113 people were surveyed. The studies enabled findings related to medical, psychological and social services; the physical environment and safety and how these aspects interacted with quality of life and satisfaction with services.

A. THE PARADOX OF OVERALL SATISFACTION

In Belarus, Georgia and Ukraine, the research revealed an interesting paradox with respondents giving relatively high ratings on general satisfaction with the respective OAT programme but, paradoxically, giving low ratings to specific services or to their own health. In Georgia¹⁰, about two-thirds of respondents expressed satisfaction with the OAT programme but only one-third were satisfied with their quality of life and health. In Belarus, where



only 24%

or respondents said they were satisfied with their state of health

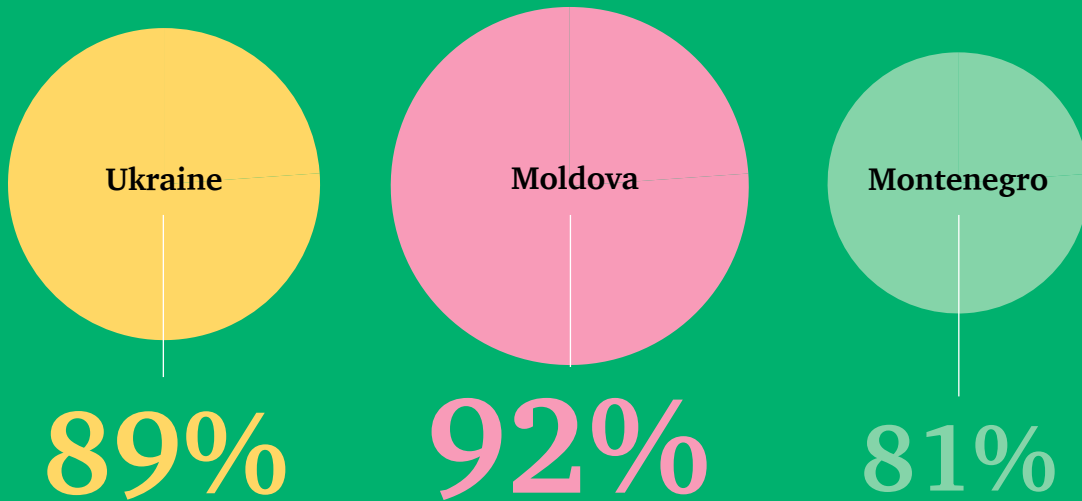
72%

said they were satisfied with the OAT service and the authors concluded that *OAT programme participants see the programme as reduced to a service of dispensing their medicine and not the full complex of interventions, including social services and harm reduction that are offered.*

In Ukraine,¹¹ authors pointed out a similar paradox whereby, “qualitative research suggests that they are happy with the opportunity to take the medicines but less satisfied with the services themselves”.

When asked to clarify what was satisfying about the services, one respondent stated, “*The medicine is satisfying to me*”. In Moldova too, the authors noted that *people, “tended not to be aware of other services offered and thought of it only as a programme to dispense the medicine”¹².*

Given the degree to which the medicine is necessary for clients to function in daily life



of respondents, respectively, felt that they need OAT to function in their daily lives^{13, 14, 15}. It is not surprising that clients express satisfaction with their access to such an essential medicine. The dynamics were similar in all countries and the research conducted in each revealed important details about how client satisfaction and quality of life might be improved.

B.HEALTH AND MEDICAL SERVICES

There was a general tendency for respondents to have relatively negative evaluations of their own states of health. Only slightly more than a third of study respondents in Georgia¹⁶ being satisfied or very satisfied with their own health, and only 23% in Belarus¹⁷ feeling satisfied with their health. In Estonia though, 77.2% felt that their health was average or better than average¹⁸. A higher portion of participants in Estonia rated the healthcare they received at the OAT service as average, good or very good at 86.2%; in Moldova, 56.1% said theirs was good or very good¹⁹; in Ukraine, 49% said theirs was satisfactory; and 54% in Belarus were satisfied or very satisfied with their medical care. In Montenegro, general satisfaction with the OAT programme and its services positively affected the assessment of all 4 domains of QoL²⁰.

METHADONE VERSUS BUPRENORPHINE

There were mixed findings about the impact of methadone versus buprenorphine on quality of life, with respondents on the methadone programme in Georgia²¹ scoring lower in physical, social and psychological

aspects of QoL and with respondents on methadone in Ukraine²² also showing lower QoL. However, in Montenegro, there was no significant difference in QoL between participants receiving the different medicines²³.

DOSE

There was strong variation between the countries on how respondents felt about the adequacy of their medicine dose.

In Montenegro, where an individual approach to dose adjustment is taken,

70.6%

stated that their dose was adequate.

There was an association between satisfaction with the dose level and assessments of the psychological, social and environmental domains of quality of life of individuals²⁴.

In Georgia²⁵

90.5%

In Estonia²⁶

95.4%

of respondents, respectively, felt they had an adequate dose of their substitution medicine.

In Moldova²⁷

In Ukraine²⁸

51% and 49%

of respondents, respectively, felt the dose was adequate.

Furthermore, rates of injecting drug use in the last 30 days varied greatly between the countries, ranging from only 9% in Montenegro to 58% in Estonia in Estonia²⁹.

LINKAGE TO HIV AND HCV SERVICES

Rates of HIV and HCV were high among participants in all countries. In Ukraine, HIV and HCV were reported by 23.6% and 58% of study participants, respectively, and having HIV or HCV was linked with a lower QoL³⁰. In both Georgia and Montenegro, having HIV or HCV also had a negative impact on QoL^{31, 32}.

Access to HIV and HCV related services varied among the countries. Access to HIV and HCV related services varied among the countries. In Georgia, 85% of the sample was tested for HIV and HCV, of which only 6 respondents were HIV-positive and only 1 was not on antiretroviral therapy (ART). The



In Montenegro, authors noted that the referral system was better for participants taking methadone than those taking buprenorphine, commenting that this was due to the fact that the methadone programme commenced earlier and benefitted from Global Fund resources which had been used to build the referral system; the different service providers knew each other and continued referrals after Global Fund support had ended.

prevalence of HCV among the tested respondents in Georgia was 59.8%, of which 17% had never received treatment and 3.9% were being treated during the study period. In Moldova, almost all respondents (96.5%) had been tested for both HIV and HCV, of which 18.8% were living with HIV, of whom 95.8% were receiving ART. For HCV, 6.1% were currently being treated and 33% had been treated in the past³³. In Belarus, access to ART for respondents living with HIV was high at 96.3%, while access to treatment for HCV was only 24.4%³⁴. In Montenegro, 81.1% of respondents had been tested for HIV but only 4 respondents were living with HIV and only of whom

was on ART. Eighty percent (80%) had been tested for HCV and 13.6% were positive, of which 10% had not been treated. The respondents who were not treated attributed it to the fact that they did not pursue it themselves or gave it up due to complicated medical procedures³⁵.

In Montenegro, authors noted that the referral system was better for participants taking methadone than those taking buprenorphine, commenting that this was due to the fact that the methadone programme commenced earlier and benefitted from Global Fund resources which had been used to build the referral system; the different service providers knew each other and continued referrals after Global Fund support had ended.

C. PSYCHOSOCIAL SUPPORT: IMPORTANT BUT INADEQUATE

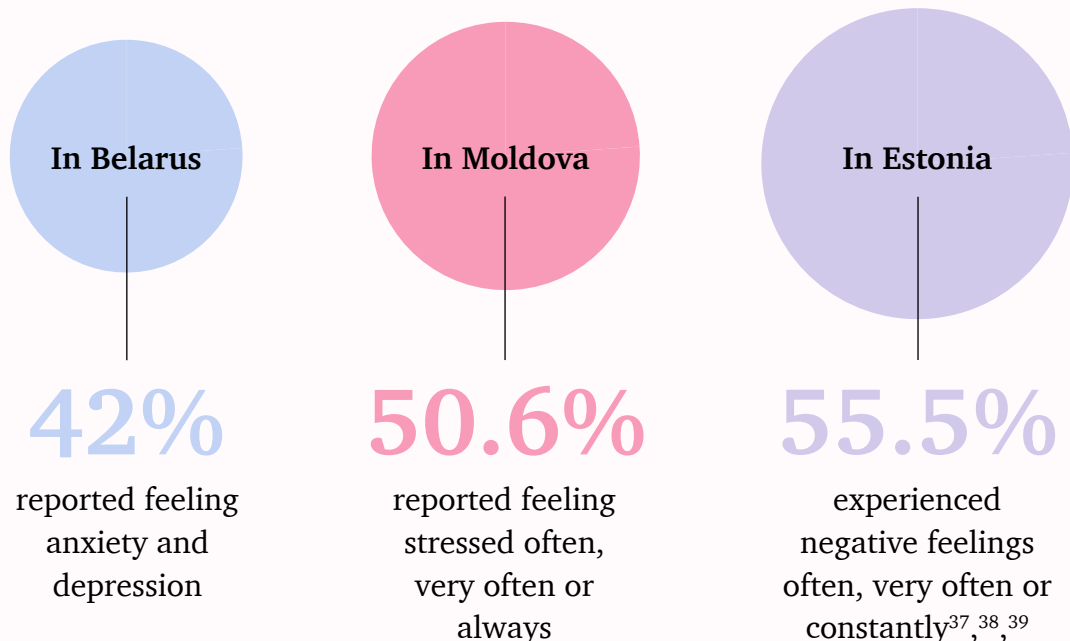
In all countries studied, OAT services were designed to provide psychosocial support to their participants, but the research showed that there were serious deficiencies in availability, staffing, use, and satisfaction with these services and also that these services have the potential to significantly improve client quality of life and health outcomes.

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In Georgia, where only 37% of respondents were satisfied with the psychosocial support offered, the authors highlighted, “the beneficiaries of the programme rarely use services other than receiving substitution medicine, such as consulting a social worker to meet other needs beyond medical needs, although the results clearly show these needs in both mental health and social condition (symptoms of anxiety and depressed mood, unemployment or low income)”³⁶. Similar dynamics were noted in the other countries.

PSYCHOLOGICAL SUPPORT

Feelings of psychological distress were common among respondents in all countries.



In Moldova, 42.8% said they would see a psychologist but only 16.1% actually did, and 61.6% said there was no psychologists at their OAT site. For those who did see psychologists, only 24.4% had a positive emotional experience during



In both Georgia and Moldova, the authors noted that negative psychological states of programme participants had a statistically significant impact on all 4 domains of their quality of life.

their contact, and 1-in-4 rated it as a stressful experience⁴⁰. In Georgia, only 38.8% of respondents said they would expect to seek help from a site-based psychologist, if needed⁴¹; this level was 44% in Ukraine. Also in Ukraine, interaction with psychologist was felt to be focused more on controlling off-site drug use than promoting improved psychological wellbeing⁴². In both Georgia and Moldova, the authors noted

that negative psychological states of programme participants had a statistically significant impact on all 4 domains of their quality of life. The Georgian authors highlighted that a pilot programme with psychosocial support integrated into the OAT programme showed considerable improvements in quality of life⁴³. By contrast, in Belarus, 85% of those who had appealed for the help of a psychologist were satisfied with the service.

SOCIAL SERVICES

The Montenegro study showed that receiving social support had a statistically significant positive impact on the psychological domain in the quality of life of respondents⁴⁴. In Montenegro, 70.8% of respondents stated that they would seek the help of a social worker if it was available and only 6% had used such a service. Thirty-seven percent (37%) stated that there were no social workers in the respective centre and only 28.4% of respondents were satisfied with psychosocial protection⁴⁵. In Moldova, only 1-in-5 respondents used the services of a social worker and 68.2% said that there was no social worker



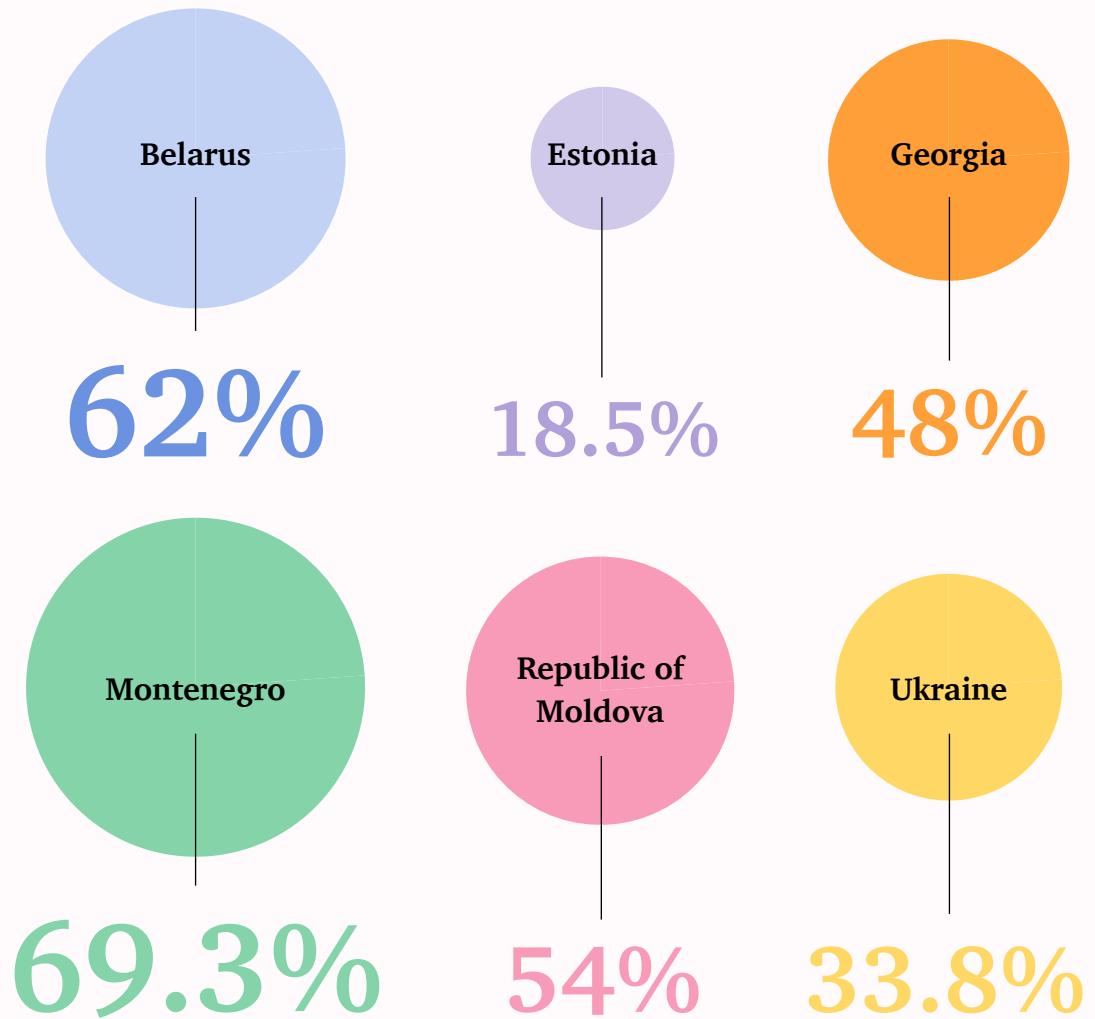
In Moldova, 74.3% of respondents said their respective site had peer counsellors and 62.4% of those had used that service, with 29.4% using such services regularly. Peers were often cited as a main inspiration for people joining the programme. In Belarus, 79.4% of those who had used the service of a peer support specialists were satisfied or very satisfied with that service.

at their respective site. In Ukraine, respondents noted that the services felt like an ‘assembly line’ designed to ensure that they were following procedures strictly, with only 34% satisfied with the service⁴⁶. In Belarus, the service seemed to have stronger performance, with 48.8% having used a social worker in the last 6 months, of which 8.6% had used it frequently⁴⁷.

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EMPLOYMENT: PROBLEMATIC AND HINDERED RATHER THAN HELPED BY THE SERVICES

Unemployment



Unemployment was a very important issue for respondents of all countries, ranging

from **18.4%** to **69.3%**
in Montenegro in Estonia

Unemployment has a significant impact upon the quality of life of OAT programme participants.

In Georgia, QoL scores in all 4 domains were lower among respondents who did not have a job⁵⁰. In Montenegro, unemployment had a statistically significant negative impact in the social domain of respondents, while receiving social support had a positive aspect on their psychological domain⁵¹. In Ukraine, unemployment had a statistically significant link to a lower quality of life in all 4 domains⁵².

There are features of the OAT programmes that hinder their participants from becoming employed. In Belarus,

35%

of respondents said they **had difficulties getting work because of the programme**⁵³.

The most common reasons for not working include

- being registered as a drug user ('narko-uchet');
- rejection when the employer learns of participation in the OAT programme;
- not being able to work in certain specialties as an OAT participant;
- and problematic working hours of the OAT service.

45%

mentioned that not being able to have **a driving license is problematic.**

In Moldova, being registered as a drug user is seen by OAT clients as a major barrier to employment⁵⁴. In Montenegro, the authors noted that while the working hours are established with the convenience of clients in mind,




OAT programme policies and practices also impede employment and the social support they offer does not adequately help participants to overcome these and other barriers to employment.

programme hours still inhibit the ability of people to get to work⁵⁵. OAT programme policies and practices also impede employment and the social support they offer does not adequately help participants to overcome these and other barriers to employment.

D. OAT PROGRAMME STAFF: IMPORTANT BUT INADEQUATE

Respondents in the different countries expressed the view that the OAT clinic staff had important roles to play in their treatment outcomes. In Moldova, 89.8% felt that attentive relations by OAT clinic staff was important or very important for their participation in the programme and relations with medical staff was the single biggest factor in the satisfaction of clients with the service (mentioned by 42%)⁵⁶. In Montenegro, 79% claim that support and care from staff is very important for them to continue with the programme⁵⁷. In Belarus, where 72% of respondents were satisfied with the OAT services, 75% of those indicated that medical staff had a major role in their satisfaction⁵⁸. In Estonia, 48.7% feel that OAT programme personnel have an important impact on their continuation of treatment and, in Ukraine, 59% felt the same way⁵⁹.

 Though the tendency for staff to be influential in a positive way is clear, it was also apparent that the programmes were understaffed.

Though the tendency for staff to be influential in a positive way is clear, it was also apparent that the programmes were understaffed. In Montenegro, group therapy and occupational therapy are unavailable, and most centres lack full time psychologists, psychiatrists and social workers. In Belarus, Moldova, and Montenegro, authors highlighted that staffing is inadequate for the quantity of programme participants. In Moldova, the authors concluded that the gaps in the provision of psychological, social, legal and case management services need to be addressed. In Belarus, the authors noted that though clients are officially to be served by multidisciplinary teams, it is not being carried out effectively. In the opinion of clients, this is due to medics not being paid adequately for their work⁶⁰.

E. PHYSICAL ENVIRONMENT AND SECURITY

The physical environment and security at OAT sites, where many people still need to make a daily visit, has an impact on the quality of life of clients. In Montenegro, there was an association between how people felt about the physical environment at the programme and how they felt about their overall environment as a domain of their QoL. There was also a link between their satisfaction with the environment of OAT sites and their satisfaction with psychological and physical domains of QoL⁶¹.

In Belarus, 88% of participants said that the physical setting is comfortable⁶². In Moldova, 86.7% considered the site to be clean and 59.2% considered it to be spacious enough⁶³, although 27.5% said they were not satisfied with the physical setting. In Montenegro, only 35.6% were satisfied with the physical environment, though 75.5% felt the facilities were clean⁶⁴. In Estonia, 60% thought the space was adequate and 83.8% felt the facility was clean. In Montenegro, Ukraine and Moldova, recipients mentioned problems with toilets at the facilities, including the lack of toilets or toilet doors not closing^{65, 66, 67}.

SAFETY AND CONFIDENTIALITY

The study in Montenegro showed an association between how safe a person feels in the programme and their QoL⁶⁸. In Georgia, nearly half of the participants felt safe at the OST site (44.6%), whilst more than half (55.4%) felt unsafe⁶⁹. In Ukraine, 65% of respondents felt safe at the site. In both Belarus and Moldova, respondents felt safer at the OAT sites than they did outside^{70, 71}. In Montenegro, 72.3% felt safe in the programme but there were variations between services, with as many as 30.3% in one centre not feeling safe; in larger centres, people felt less safe⁷². Furthermore, in Estonia, 45.6% were either not sure at all or rather not sure about the confidentiality of their personal data⁷³.

In Montenegro, where

31.8%

of respondents had little or no confidence in the security of their personal data, those who had confidence in such security had higher ratings in all aspects of their personal lives⁷⁴.

In Georgia, **only a third of respondents felt sure about the confidentiality of their data**⁷⁵.

In Moldova,

47.4%

of respondents felt that the confidentiality of their data is not guaranteed and the majority of them had experienced situations when confidentiality was violated⁷⁶.

Inadequate premises of confidential counselling sessions with OAT centre staff is common in each country. In Moldova, 24.7% of respondents noted that there is not a place where you can have a confidential conversation with a doctor. Respondents highlighted that in Chisinau and Balti, where there are offices that enable confidentiality, such offices are not always used⁷⁷. In Montenegro, centres are required to have a place for private conversations with a doctor, but only 47.3% mentioned that they always had the possibility of having a private conversation with a doctor⁷⁸.

Inadequate premises of confidential counselling sessions with OAT centre staff is common in each country.

ACCESSIBILITY AND TAKE-HOME DOSES

Given that many participants must still go to the sites every day to get their medicine, accessibility of the sites is important. In Montenegro, people who found it difficult to get to the programme had lower ratings in their QoL environment domain. There were a range of differences between the countries on how participants felt about accessibility, with 75.3% of participants in Estonia finding it convenient but only 60.7% in Belarus, whereas 55% in Ukraine had the same feeling^{79, 80, 81}.

As discussed above, visiting the OAT sites every day is taxing for participants and can make it difficult for participants to work. Offering take-home doses, though, was acknowledged as a good practice, improving conditions for participants and optimising costs at sites, but uptake of the practice remains limited as both

Visiting the OAT sites every day is taxing for participants and can make it difficult for participants to work. Offering take-home doses, though, was acknowledged as a good practice, improving conditions for participants and optimising costs at sites, but uptake of the practice remains limited as both inertia around change and fears about security (leakage of medicines from the system to the street) causes resistance to make such a change.

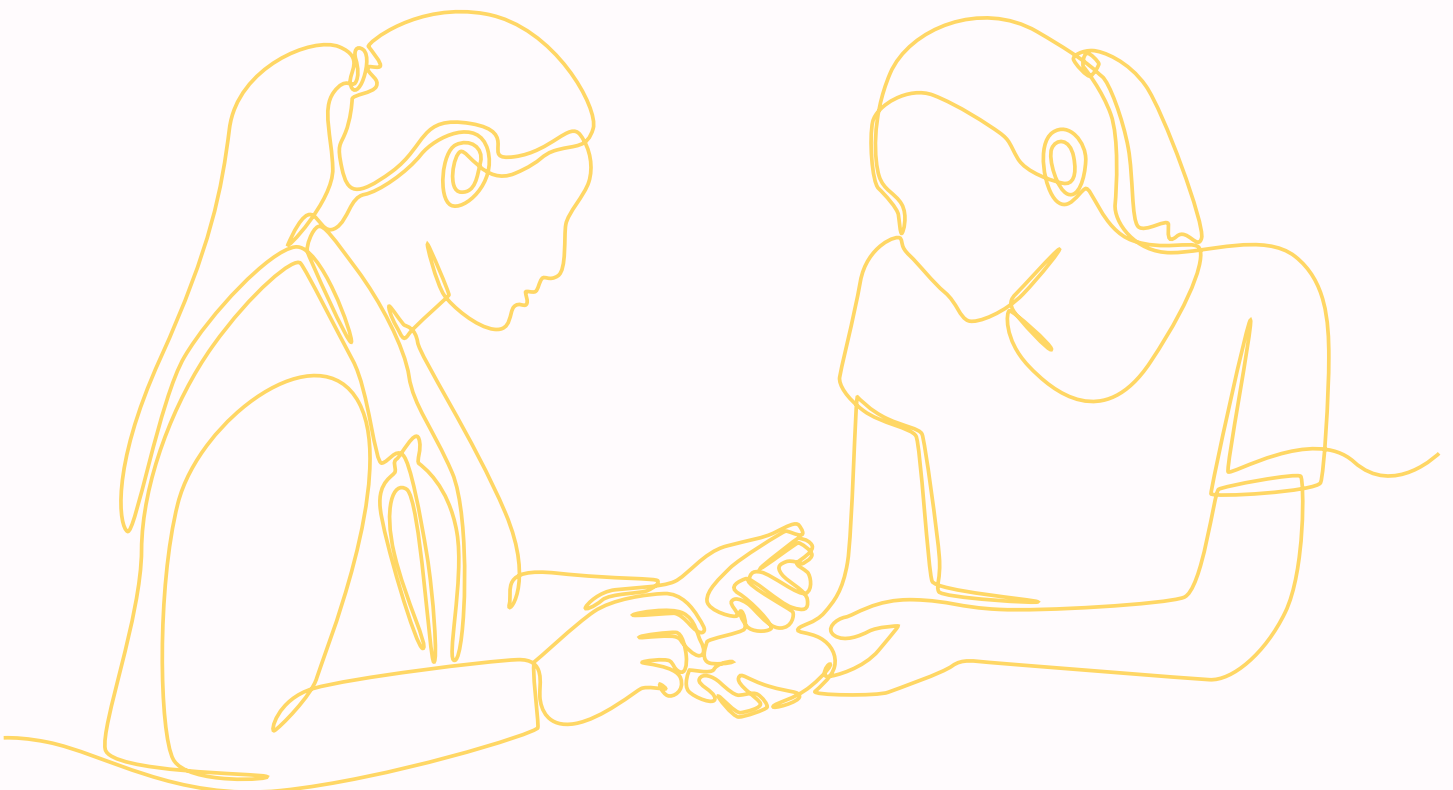
inertia around change and fears about security (leakage of medicines from the system to the street) causes resistance to make such a change. During the COVID-19 pandemic, countries broadened their application of take-home dosing policies. In Moldova, clients were able to receive take-home doses and, at the time of the study, about 51% received medicines 2 or 3 times a week and 31% received it once a week. There were two cities where daily dosing continued even during the COVID-19 pandemic although 93.1% of participants overall were happy with the changes that happened during the pandemic. Two-thirds of participants would be in favour of video observed therapy (VOT) if it enabled take-home

dosing⁸². In Montenegro, 61.2% of participants attend once a week and 22.3% come once a day. An individual approach is applied with urine tests needing to be negative for psychoactive substances that then leads to dosing twice or

once a week⁸³. Those who have been in the programme longer are more likely to be among those who come once a week⁸⁴. In Georgia, a majority of study participants (72.7%) were going to their respective OAT site once every 5 days and 27.3% attended daily to receive medication. However, according to the results of the quantitative research, daily attendance gives beneficiaries some psychological comfort⁸⁵, with the studies in both Georgia and Montenegro finding that daily attendance gives clients some psychological comfort^{86, 87}. In Belarus, though, 87% of respondents noted that QoL was better with take-home doses, citing that it enabled childcare, travel, employment and lowered the risk of contracting COVID-19⁸⁸.

PRISON

The most egregious impingement upon physical environment and security faced by programme participants was imprisonment. All countries reported high levels of participants having experienced imprisonment, with Moldova having the lowest rate at 49.8% and Belarus having the highest at 81%. This indicates that all countries require drug policy reform.



VII. RECOMMENDATIONS

- Quality of life and client satisfaction should be monitored frequently and routinely as part of the monitoring and evaluation of OAT programming.
- Community-led monitoring should be leveraged for the effective monitoring and evaluation of OAT programmes as such enabling collaboration with communities helps to understand how best to improve client satisfaction and their quality of life.
- Referral systems between OAT programmes and HIV, HCV and TB-related prevention, testing, treatment and support programmes should be strengthened.
- Psychosocial support provided at OAT programmes should be enhanced.
- OAT service hours should be adjusted to enable OAT participants to more easily pursue employment.
- Individual approaches to take-home doses should be enabled.
- Decriminalisation would reduce imprisonment of OAT clients and, until decriminalisation is instituted, continuity of access to OAT programming should be guaranteed for people experiencing detention.
- Quality of life and client satisfaction studies can be leveraged to counter efforts to cut costs or to 'optimise' spending which would otherwise push for the elimination of psychosocial support as a service that is too costly.

ANNEX 1

List of interviewees

- | | |
|--|--------------------------------|
| → Vytalij Rabinchuk
PULS Community Centre | → Ivana Vojvodic
Juventas |
| → Marija Mijovic
LINK | → Elena Antonova
LUNEST |
| → Oleg Dymaretski
and Igor Kozak
VOLNA | → Zaza Karchkhadze
Rubikoni |

ANNEX 2

Resources

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