DOCUMENTATION OF BEST PRACTICES

of community-led monitoring (CLM) in Ukraine

2026

THE EXPERIENCE OF ORGANISATIONS OPERATING TO PROTECT THE RIGHTS AND INTERESTS OF PEOPLE WHO USE PSYCHOACTIVE SUBSTANCES (CO CF PUD.UA) AND WOMEN LIVING WITH HIV (CO "Positive Women")

ELTON JOHN
AIDS FOUNDATION

HAC
HEALTH ADVOCACY
COALITION

This document has been prepared as part of the project "Empowering Civil Society Organisations and Community-Based Organisations in Ukraine to Leverage CLM Results to Advocate' by the Health Advocacy Coalition (HAC) with the financial support of the Elton John AIDS Foundation (EJAF)

This is an automated translation of the Ukrainian version of the material

WHY THIS EXPERIENCE IS WORTH DOCUMENTING

Community-led monitoring is no longer merely a donor requirement or a reporting formality. **CLM has become a powerful tool for driving systemic change through witness generated by the patient communities, demonstrating that:**

- their experience of accessing health and social services matters,
- their lived personal histories constitutes valid evidence,
- their voices that must be heard in decision-making processes.

On a global scale: without high-quality CLM, it is impossible to achieve the 95-95-95 targets. The continuum of HIV services (from testing to viral suppression) breaks down where government monitoring systems fail to capture people's experiences. CLM bridges this gap: it tracks where and why people drop out at each stage, and provides an evidence base for intervention.

In Ukraine, this has been confirmed under extreme conditions: during a full-scale war, the displacement of millions of people, severely disrupted healthcare infrastructure, disrupted logistics chains, and a lack of coordination between different branches and levels of government. In this context, CLM effectively functions as an early warning system.

What happened when patient communities stopped waiting for ideal conditions and created the tools that were lacking? This case study documents the practical experience of developing and using CLM as a tool to influence decision-making within the healthcare system. Teams from the charitable organisations PUD.UA **(representing people with experience of using psychoactive substances)** and "Positive Women" **(representing women living with HIV)** did not simply collect data. They designed tools, trained monitoring specialists, collected and systematised a large dataset, analysed the results and presented the evidence base to regional health authorities – and some of the necessary changes have already been implemented (with others to be integrated shortly).

In some regions, funding has been secured from local budgets for essential medicines and nutrition for the children of women living with HIV. Training sessions on combating discrimination have been held for nearly 100 healthcare workers in healthcare facilities in the Zaporizhzhia and Mykolaiv regions. Service delivery pathways have been reviewed. And all this has been achieved within less than a year.

The aim of this publication is **not simply to celebrate what has been achieved, but to make this experience replicable.** We are documenting the architecture of the tools, the decisions made, typical real-world challenges, and the factors that made these changes possible. In other words, this is not about tools in a vacuum, but about how they can be applied within a system of other components. We are doing this so that organisations in Kyrgyzstan, Kazakhstan, Moldova and other EECA countries or those with a similar context (as well as in Ukraine – for communities not yet covered by CLM) can learn from this experience, rather than starting from scratch or taking unnecessary steps.

This is a living document. The integration of CLM data into the Central Database of the Public Health Centre of Ukraine is still ongoing. The tools continue to be refined, and will be further improved in stages. The evidence base is growing. What we are presenting here is an honest account of the first cycle of work: its results, gaps, and potential.

Serhiy Dmytriyev
Executive Director of HAC

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PART B: Description of successful practices

LIST OF ABBREVIATIONS

ART	antiretroviral therapy
HIV	human immunodeficiency virus
HPV	human papillomavirus
IDPs	internally displaced persons
GF	Global Fund to Fight AIDS, Tuberculosis and Malaria
PrEP	pre-exposure prophylaxis
DOH	Department of Health
WLHIV	women living with HIV
HCF	healthcare facility
OST	opioid substitution therapy
HR	harm reduction
STIs	sexually transmitted infections
PWID	people who inject drugs
PLHIV	people living with HIV
M&E	monitoring and evaluation
MOD	Ministry of Defence of Ukraine
MoH	Ministry of Health of Ukraine
NGO	non-governmental organisation
PSD	Psychoactive Substance Dependence
PCR	polymerase chain reaction; laboratory method for detecting the pathogen’s genetic material (DNA or RNA)
PHC	primary healthcare
PMHC	prevention of mother-to-child transmission of HIV
SRH	sexual and reproductive health
EECA	Eastern Europe and Central Asia
TB	tuberculosis
CDB	central database of PHC
PHC	Public Health Centre, of Ministry of Health of Ukraine
Health Centres of the State Penitentiary Service	Health Centres of the State Penitentiary Service of Ukraine
CCM	Country Coordinating Mechanism
CLM	community-led monitoring
EJAF	Elton John AIDS Foundation
HAC	Health Advocacy Coalition

PART A.
An Approach to Developing CLM Tools to Influence Decision-Making in the Healthcare System

1. CONTEXT FOR THE DEVELOPMENT OF A NEW CLM TOOL IN UKRAINE

1.1 Epidemiological and socio-political context[1]

Ukraine remains one of the countries with the highest burden of HIV infection in the European Region. As of 1 January 2026,

130 676	89%	▶	97%	▶	92%
people living with HIV were registered	**of the estimated number knew their status**		**of them were receiving ART**		**of patients on treatment achieved viral suppression (<50 copies/ml)**

These figures indicate significant progress towards the 95-95-95 targets; however, the aggregated data masks significant inequalities between different key population groups and regions of the country with markedly different circumstances, and moreover, the estimated number of those actually living with HIV is significantly higher.

Among people who inject drugs (PWID), the cascade remains significantly lower than the national figures: according to the latest available data from biobehavioural studies, only 58% of HIV-positive IDUs know their status, 70% of them are receiving ART, and 74% achieve viral suppression. **The estimated number of IDUs in Ukraine is 278,318. OAT coverage stands at 32,233 patients** (77.7% of the target, taking into account all forms of ownership of facilities where OAT is provided), whereas coverage by comprehensive prevention services reaches only 53% of the estimated number (against targets of 80% by 2025 and 90% by 2030). In 2025, 64% of new HIV cases were diagnosed at advanced stages – indicating systemic failures in early detection.

Women living with HIV (WLHIV) face additional gender-specific vulnerabilities.

In 2025, 160,231 pregnant women were tested for HIV, of whom 196 tested positive (a 28% decrease compared to the previous year). Mother-to-child transmission of HIV has been reduced to 1.5% according to PCR tests.

At the same time, WLHIV face hidden barriers – annual financial costs for infant formula and lactation-suppressing medication, limited access to SRH services, and breaches of confidentiality – none of which are recorded by the routine state monitoring and evaluation (M&E) system for HIV response measures in Ukraine.

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[1] The data used in this section is taken from presentations delivered on 30 March–1 April 2026 during the National Strategic Dialogue “Sustainability and Resilience: Strategic Alignment of Investments by the Global Fund, the US Government (USG), Development Partners and Domestic Funding for the Fight against HIV/TB’. The aim of the event was to coordinate the response to HIV and tuberculosis in Ukraine in the context of military aggression and in the post-war period – including the preparation of a funding request to the Global Fund under the 8th grant cycle for 2027–2029

> "We only have enough medication to last a month, and after that it's anyone's guess – that's why we were told to leave immediately. But we've only just arrived here, having fled the war in our hometown: it's simply physically impossible for us to move again. Treatment shouldn't be interrupted because of situations like this. It's extremely stressful and risky."
>
> **Iryna, 38, Donetsk region, OST patient**

Russia's full-scale invasion of Ukraine in February 2022 significantly worsened the situation. The war destroyed the medical infrastructure in the affected regions, led to the collapse of a number of essential service systems, reduced the purchasing power of ordinary citizens and, consequently, people's basic standard of living, disrupted ART supply chains, caused the displacement of over 6 million people, and resulted in a further nearly 5 million people becoming refugees in other countries. For key population groups – people with experience of using psychoactive substances, sex workers, men who have sex with men, prisoners, and transgender people – the war has compounded existing barriers of stigma, discrimination and criminalisation with the acute consequences of displacement and the collapse of essential services. For PWID, the impact of armed conflict is specific: changes in drug markets, the emergence of new supply routes, new risk patterns among young people, and reduced access to substitution therapy in frontline regions. For women living with HIV (particularly pregnant women and mothers), the war brings additional risks of ART interruption, loss of contact with healthcare facilities, and limited access to reproductive health services.

In this context, the role of community-led monitoring (CLM) becomes not merely important, but critical. CLM functions as an early warning system – something that government data systems cannot provide on their own: after all, patient community organisations on the ground, when addressing specific challenges, identify problems much earlier and more reliably than they appear in national statistics (if they appear at all). It is precisely this ability to detect barriers and disruptions early that is crucial for maintaining the continuity of the 95-95-95, as it enables a timely response to the risks of treatment interruption, loss of patients during follow-up, and failure to achieve viral suppression.

1.2 The problem that CLM solves

Despite the considerable experience of Ukrainian civil society organisations in data collection and substantive work with patient communities, **the CLM landscape in Ukraine was characterised by fragmentation prior to the launch of this project.** When monitoring specific parts of the service continuum (OST, ART, STI services, reproductive health), organisations used paper questionnaires or digital equivalents (such as Google Forms or SurveyMonkey) without standardisation or systematic application. Data was collected regularly, but it was impossible to compare it across regions or over a sufficient time period in relation to a specific factor, and therefore to generalise it correctly – consequently, comprehensive analysis rarely took place (and when analysis did occur under certain conditions, the results rarely reached decision-makers in a usable form). Consequently, patient-generated data remained disconnected from decision-making.

This creates not only methodological gaps but also tangible failures in achieving the 95-95-95 targets. Without systematic data from patients, it is impossible to determine why a particular person does not know their HIV status, why they discontinue ART, or why they do not achieve positive treatment outcomes. Without this knowledge, the healthcare system responds in a generalised manner and overlooks systemic gaps that recur year after year.

At the same time, the national M&E system lacked an effective channel for receiving feedback from key communities. The Public Health Centre (PHC) was willing to integrate CLM data but required a structured, standardised format. **The gap between the existence of data and its use for decision-making was a systemic problem – one that this project aimed to overcome.**

1.3 Architecture of the developed CLM toolkit

The project, funded by the **Elton John AIDS Foundation (EJAF)** and coordinated by the Health Advocacy Coalition (HAC), involved three sub-grantee organisations: charitable fund “PUD.UA” (Ukrainian Network of People Who Use Drugs), the organisation “Positive Women” and the organisation “VONZH VONA” (All-Ukrainian Association of Women with with experience of using psychoactive substances). Each team developed CLM tools tailored to the needs of their communities.

This material documents the experience of two organisations – “PUD.UA” and “Positive Women” – whose pilot data became the first CLM datasets integrated into the Central Database (CDB) of the Public Health Centre (PHC).

The project was implemented in close coordination with the PHC, which incorporated the integration of CLM data into its strategic work plans for 2024–2026. This institutional readiness is the result of consistent advocacy work by HAC, which has created the conditions for a transition from fragmented data collection by individual communities to comprehensive institutional use at the state level.

The HAC’s role in the project was defined as a technical partnership: developing a shared architecture for digital tools, an analytical framework and training materials; coordinating sub-grants; and facilitating communication between communities and national institutions. Crucially, HAC did not manage the monitoring process – community organisations independently set priorities, developed questionnaires and used the data for advocacy.

> “Since I found out about my HIV status in 2013, I have encountered prejudice dozens of times whilst accessing healthcare services. Every single time, in the literal sense of the word, when I disclosed my diagnosis, it did not merely cause discomfort or alienation in the person I was speaking to – it instantly hindered my access to the necessary care.
>
> To avoid such situations, I am forced to seek treatment at medical facilities in the regional centre of Poltava – away from where I live. And with the outbreak of full-scale war, this has become difficult, to say the least, from a logistical point of view, as shelling, air raid alerts and damaged infrastructure have made the journey between the cities difficult and dangerous. “To get from Kremenchuk to Poltava or back, I have to use several modes of transport, which takes up a significant amount of time and resources.”
>
> **Iryna, 34, Kremenchuk, woman living with HIV, mother of a 13-year-old son**

1.4 Stakeholders, roles, coordination

The project model stipulates that the development, administration and use of the CLM tool are carried out directly by organisations representing patient communities – those whose experiences are the subject of the monitoring. The PUD.UA brings together people with experience of using psychoactive substances, while “Positive Women” – women living with HIV. This grassroots approach defines the nature of the entire process: **representatives of the target groups act not only as respondents but also as co-authors of the tool – from formulating questionnaire questions to setting advocacy priorities.** This approach ensures the tool’s responsiveness to real needs whilst strengthening trust within patient communities in the monitoring process.

At the same time, the model does not envisage community organisations working in isolation. As a technical partner, HAC is responsible for designing the digital tool, developing analytical approaches, creating training materials and, in certain cases, coordinating sub-grant funding. The PHC acts as an institutional partner: it supports the integration of CLM data with national monitoring systems and participates in shaping approaches to data exchange. At the regional level, the implementation of changes takes place with the support of local health authorities.

> “When you face stigma or discrimination, when your rights are violated in society or within certain institutions – that is precisely what motivates you most to stand up for yourself. What’s more: it encourages you to learn more about protection mechanisms, the limits of your capabilities and rights, the responsibilities of others, potential harm, the reasons for people’s misunderstanding of those like you, and disclosure of your status. And once you’re informed, you can help others too”
>
> **Zhanna, 60, Lviv region, living with HIV**

Implementation is organised across three interrelated levels that function as a single system:

At **A STRATEGIC LEVEL,** the HAC works with community organisations to define the CLM methodology, data quality standards and approaches to data collection (including gender-sensitive approaches). It also liaises with national bodies – the Public Health Centre (PHC), the Central Database and relevant working groups. The HAC develops chatbot architecture, analytical frameworks and training materials, but does not, as a matter of principle, manage the monitoring process itself.

THE ORGANISATIONAL LEVEL encompasses both national and regional activities. National teams develop data collection tools in collaboration with communities, carry out analysis, prepare advocacy materials and present the results at national forums. Regional coordinators test the tools, recruit respondents, oversee the data collection process and provide feedback tailored to the local context. In some models, there is a clear internal division of roles between programme coordination, monitoring and strategic leadership, with coordination taking place through regular meetings between levels.

At **THE ADVOCACY LEVEL,** the results of monitoring are regularly presented by key community organisations at coordination forums – Coordination Councils, CCMs and thematic sub-groups. In parallel, a dialogue is being conducted with national institutions to improve data-sharing systems, and changes in policies, regional plans, budgetary decisions and the practices of healthcare facilities are being monitored.

The strength of the model presented in this material, which has proven successful in the Ukrainian context even during the war, lies in the integration of three components: patient community expertise (direct involvement of people with relevant experience), technical support (high-quality tools and analytics) and institutional integration (interaction with state bodies). It is this combination that allows not only for the collection of data, but also ensures its systematic use to influence decisions, policies and the quality of services at national and regional levels.

2. APPROACH TO DATA COLLECTION AND ANALYSIS

2.1 Definition of CLM within the project

Within the framework of this project, **CLM is defined as a systematic, designed and community-led process of collecting, analysing and utilising data on the quality of HIV/TB programme services, barriers to access and rights violations – with the aim of shaping the necessary response programmes, decisions, actions and mechanisms on the part of state institutions.**

Three features distinguish this approach from standard satisfaction surveys or the collection of feedback from beneficiaries:

COMMUNITY-LED OWNERSHIP.

Patients and service users themselves shape the tools, set the monitoring agenda, collect and interpret data, and oversee its use. External organisations provide technical support using a participatory approach to collaboration – but do not interfere in the process itself.

EVIDENCE-BASED APPROACH.

Data is collected not merely to document experiences as such, but to generate evidence for advocacy, the creation and implementation of relevant projects and programmes to address identified challenges, and the formulation of both regional and national policies.

INSTITUTIONAL INTEGRATION.

CLM data must be integrated into existing national M&E systems so that community-generated data influences official planning and relevant mechanisms for responding to the needs of the population.

CLM in Ukraine: from fragmentation to a systematic approach

Community-led monitoring is not new to Ukraine. Civil society organisations and patient communities working in the field of HIV have many years of experience in gathering feedback from representatives of key communities, documenting rights violations and monitoring services. In particular, the REAct system, implemented by the International “Alliance for Public Health” with support from the Global Fund, has ensured the documentation of rights violations affecting key populations in their interactions with medical, law enforcement and social institutions. In parallel, in 2023, UNDP produced two analytical reports: an assessment of community-based organisations’ capacity to implement CLM and an assessment of the level of systemic integration of CLM into the HIV service sector in Ukraine – both of which identified both the potential and the structural limitations of existing practices. UNAIDS, as part of a joint UN programme, contributed to the development of a new CLM framework for Ukraine and supported the revision of the national strategy to remove legal barriers to HIV and TB services.

> 'It is of fundamental importance to us that the patient experience does not end with a single visit or survey. It must become part of a systematic analysis. Integrating community-led monitoring data into the national digital infrastructure opens up the possibility of transforming thousands of individual stories into an evidence base for improving programs, policies, and resource allocation. This is precisely how a modern public health management model, focused on people’s needs, is formed.'
>
> **Serhiy Myroniuk,**
> **Chief Specialist for Project Management and International Cooperation at Public Health Center of the Ministry of Health of Ukraine**

The model documented in this paper does not replace previous initiatives, but rather makes targeted use of the infrastructure they have established – networks of community organisations, monitoring skills, experience of engaging with state institutions, and an established culture of data collection – and builds upon it to address what was missing: digital standardisation, built-in analytics and a direct channel for integration into the state information system. Whereas data was previously collected in a piecemeal fashion and remained within organisations, it now enters the Central Database of the PHC in a standardised format – and becomes part of the very information system that the state uses for programme planning and resource allocation.

In other words, the project did not start from scratch. It transformed the fragmented experience of communities into a systematic tool for influence – building on what was already working and adding the technical and institutional components that were lacking: to move from data collection to the use of that data in decision-making.

> "Social workers used to communicate with us more; there was a sense of support. Now they're swamped with paperwork – and there's far less contact. This leads to a drop in motivation and a loss of trust, as well as a lack of practical help in everyday life. We'd like to see normal communication restored."
>
> **Oleksiy, 42, Kyiv region, client of harm reduction programmes**

2.2 The CLM cycle

In accordance with the GF's operational recommendations and the PHC's requirements for data integration, within the framework of this project, the HAC implemented the CLM process following the logic of a five-stage cycle:

DESIGN

Patient organisations identify priority monitoring issues in consultation with patients. Tools are developed or adapted to capture specific issues.

DATA COLLECTION

Trained monitors or members of patient communities who complete questionnaires independently submit structured responses via a digital tool. Data collection is continuous rather than sporadic.

ANALYSIS

Aggregated data is analysed via the admin panel dashboard. Organisations generate thematic reports on barriers, violations and gaps in services using built-in analytics.

ADVOCACY AND DIALOGUE

The results are transformed into advocacy materials and presented to relevant stakeholders: regional health authorities, the Central Government, the CCM, and donor partners.

FEEDBACK AND ADJUSTMENT

Changes resulting from advocacy are documented. Monitoring tools are revised to address new challenges and analytical gaps identified in the previous cycle.

> "What motivates me most to stand up for my rights is the sense of mutual support. Firstly, from the community and the organisation. The girls from the "Positive Women" have become like a second family to me. We support and encourage each other greatly in difficult times.
>
> Secondly, from my husband. When he found out about my status, he didn't abandon me during a difficult time. And also my little daughter – who won't let me give up or sit still. My heart beats faster at the mere thought of my child being healthy. I'm really looking forward to the paediatrician's appointment – so she can confirm that everything is fine and my child is taken off the register. Then I'll move on to my long-held dream: photography courses!"
>
> **Olena, from Cherkasy, is living with HIV, is married and is raising a 2-year-old daughter**

2.3 Theory of change

BASIC LOGIC

If patient community organisations have access to user-friendly, secure digital tools for structured data collection ▶ and if the collected data is systematically analysed and transformed into advocacy products ▶ then the communities' evidence base will reach decision-makers in a usable format ▶ leading to programme and policy adjustments ▶ and, as a result, to measurable improvements in service quality, rights protection and access for key population groups.

This theory is based on two prerequisites, which the project team worked diligently to establish: (1) the technical capacity of key community organisations to manage the tools independently and interpret the data without relying on external IT support; and (2) the institutional readiness of the PHC and other responsible bodies to receive and utilise community data. Both prerequisites required investment throughout the pilot period.

This theory of change is not a linear statement – on the contrary: it describes a sequence of conditions, each of which is necessary but insufficient without the others. The logic of each chain and the key prerequisites that the project had to create or ensure are outlined below.

Chain 1: From tool to data

Community organisations need monitoring tools, but do not always have the technical capacity to develop them themselves. At the same time, externally developed platforms often fail to take into account the specific characteristics of the target groups – such as levels of trust, digital literacy and the sensitivity of the subject matter. **The project addressed this contradiction through a co-design model: the technical partner (HAC) provided the architecture and development, whilst community organisations determined the content, wording of questions, navigation logic and engagement channels.**

PThe result was tools that communities perceive as their own – which is critical for the participation of beneficiaries who have valid reasons not to trust external data collection systems.

A key prerequisite for this chain is a low barrier to entry: anonymity, minimal completion time, a familiar interface (Telegram), and no registration. Without these features, the tool does not generate sufficient data for evidence-based advocacy.

Chain 2: From data to analytical product

Collecting data without an analytical infrastructure recreates the very problem the project was designed to overcome: the information exists, but it is not transformed into actionable insights. The theory of change stipulates that organisations must be able to independently manage the entire analytical cycle – from data collection to the generation of reports and advocacy materials – without relying constantly on external IT support. **This required investment in two areas: building in-built analytics into the admin panel (dashboards, funnels, export to Excel) and training the organisations' teams to work with data.**

A key prerequisite is the technical capacity of organisations: the ability to interpret results, identify trends and draw conclusions for different audiences.

Chain 3: From analytical product to institutional impact

Even a high-quality analytical product has no impact if it does not reach the relevant audiences in a format suitable for use. **The theory of change envisages two parallel channels of influence: (a) advocacy – through presentations at coordination platforms, thematic working groups, Coordination Councils and the SCM; and (b) institutional – through integration CLM data to the Central Database of the PHC,** enabling patient and service user experiences to be incorporated into the very same information system that the state uses for policy planning.

A key prerequisite is the institutional readiness of the Public Health Centre and other responsible bodies to receive and use community data. This readiness did not arise automatically: it is the result of consistent advocacy work by the HAC and community organisations, which continued throughout the pilot period and included several rounds of negotiations on data exchange formats, the harmonisation of indicators, and the drafting of a memorandum of cooperation.

> “If I could change two things about the healthcare system, this is what they would be:
> Instead of dealing with the consequences of illness, the focus should be on prevention. Doing this at your own expense is very expensive and few can afford it. But a solution at the state level is exactly what’s needed. That’s what I dream of for my child.
> More freely available information on prevention, free services and rights. Because doctors often don’t tell you, and even if there are medicines or treatments available, they don’t want to process the paperwork.”
>
> **Olena, 41, Mykolaiv, woman living with HIV and raising her daughter**

Chain 4: From institutional influence to change for people

The ultimate goal of CLM is not data or reports, but improvements in the quality of services, the protection of rights and access for key population groups. The theory of change recognises that these changes occur at different levels and at different speeds: allocation of funds for infant formula and lactation-suppression medication, changes in healthcare practices (training on combating stigma), regulatory steps at national level (proposals for amendments to Ministry of Health orders), and the institutionalisation of dialogue (regular consultations between the Public Health Centre (PHC) and community organisations).

Documenting these changes and their link to CLM data forms part of the fifth stage of the CLM cycle (feedback and adjustment) and provides a basis for subsequent monitoring cycles.

Risk areas in the theory of change

The theory of change contains several vulnerabilities that the project identified during implementation.

Firstly, dependence on external funding during the tool development phase – without a stable source of resources, the transition from a pilot to a sustainable operational model is risky.

Secondly, the varying pace of institutional response: regional authorities may react quickly (budgetary decisions), whereas changes at the national level require significantly more time.

Thirdly, the risk of technological dependency: if updating or maintaining the tool requires the involvement of an external developer, organisations lose some of the autonomy embedded in the model. These risks do not invalidate the theory of change, but they identify areas that require targeted management during replication.

3. THE CLM DIGITAL MODEL: SHARED ARCHITECTURE

This section describes the technical solutions common to both tools: the chatbot of PUD.UA (@volna_ua_bot) and the chatbot of the “Positive Women” (@UKRAINEpw_bot). Specific adaptations for each organisation, such as thematic modules, questionnaire formats and engagement channels, are described in the relevant sections of this document.

Before describing the specific architecture of the chosen solution, it is worth noting the broader context. Messaging apps – Telegram, WhatsApp, Viber, Signal and others – have become a powerful platform for building digital data collection tools in the field of public health. Their key advantage is an unprecedentedly low barrier to entry: users do not need to install additional apps, create accounts or register. **They interact with the tool within the very same environment they use for everyday communication.** For key population groups facing stigma, criminalisation and mistrust of formal institutions, this feature is not a convenience but a prerequisite for participation.

Most popular messaging apps provide a Bot API – a programming interface that allows you to create automated bots for structured data collection, content navigation and information provision. The Telegram Bot API, WhatsApp Business API and Viber Bot API enable the creation of modular questionnaires with branching logic, automatic saving of responses and administrative management without the need for a developer.

Compared to specialised mobile apps, the development of which requires significant resources and technical expertise from end users, messenger-based bots are a far more accessible solution – both in terms of development cost and ease of use.

At the same time, they are in no way inferior in terms of functionality: modular architecture, regional targeting, built-in analytics, data encryption – all of this is implemented via the Bot API without the need to go through app store publication procedures or require users to have technical skills beyond navigating the messenger.

The choice of a specific messaging app should be determined not by the developer's technical preferences, but by the context of the target patient community: which messaging app is dominant among the key population group in a specific country or region. In Ukraine, that app is Telegram – and this determined the platform for both tools in this project. In the context of other EECA countries – for example, Kyrgyzstan, Kazakhstan or Moldova – this could be Telegram, WhatsApp or Viber, depending on the local communications landscape. The selection principles described below remain universal.

> "At the medical commission, they spoke openly about my tuberculosis. They simply shouted that I shouldn't come near. This happened in front of other people – it was very humiliating. Nobody thought about confidentiality. And this happens literally everywhere: although I just can't get used to it."
>
> **Serhiy, 41, Kharkiv region, OST patient**

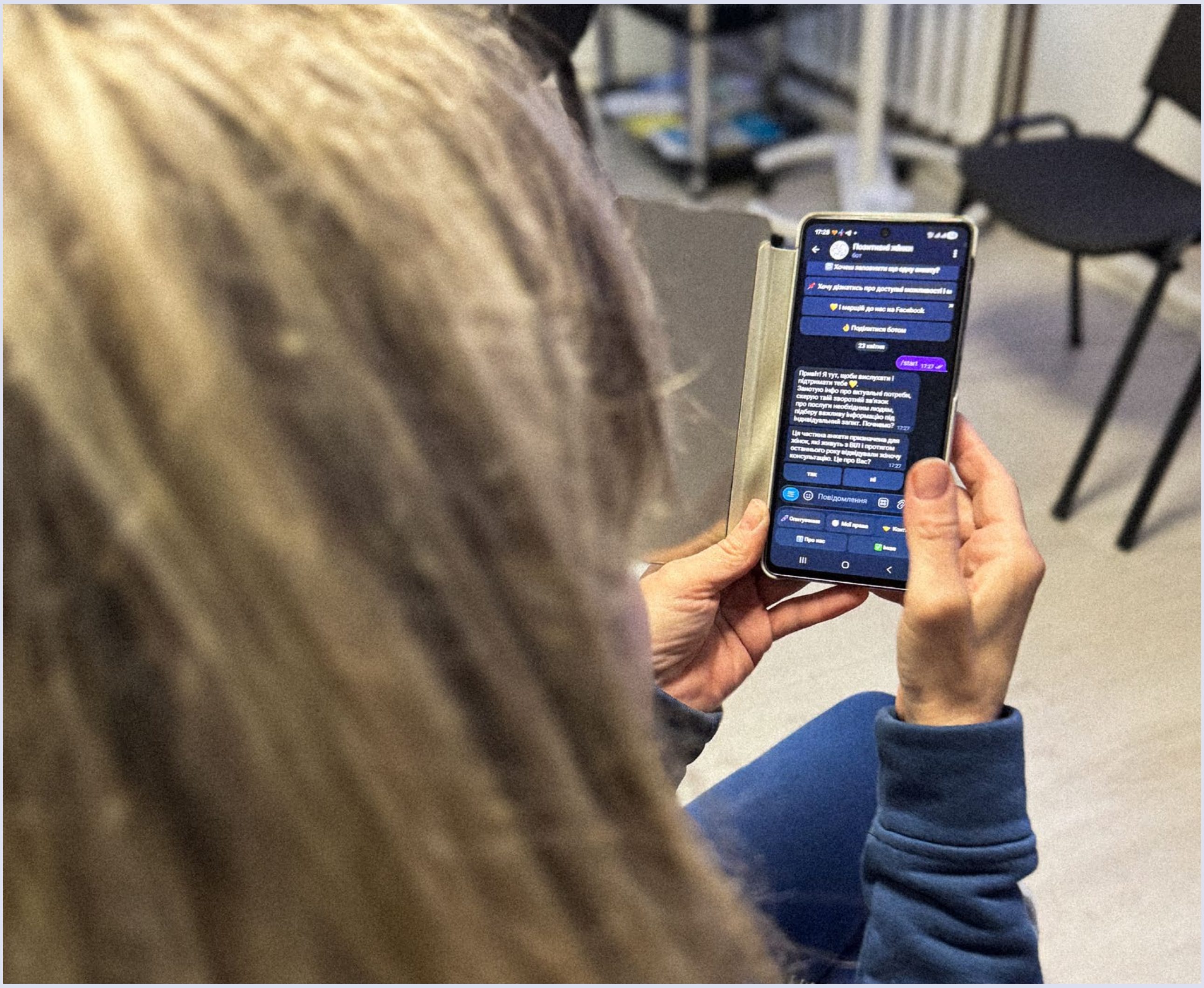
3.1 Choosing a platform

The choice of Telegram as the platform for both chatbots was not a standard technical decision – it was the result of targeted consultations with communities. Telegram is the primary communication channel for key population groups in Ukraine: in particular, for MSM and PLHIV. According to data from a pre-training survey by PUD.UA, 76% of participants were already using Telegram chatbots in their daily lives.

The platform meets the four criteria defined by the project as mandatory:

WIDESPREAD USE AMONG THE TARGET GROUP	virtually universal penetration among MSM and PLHIV in Ukraine
ANONYMITY	no requirement to register with a phone number linked to a real person
SECURITY	end-to-end encryption of direct communications, encrypted data storage
LOW BARRIER TO ENTRY	completing the survey does not require installing apps, creating accounts or technical literacy beyond the skills needed to navigate a messaging appю

The feature of invisibility is also crucial: Telegram bots are visible only to those who actively seek them out or receive a link – they carry no external markers of association with HIV services or drug use. For communities where such an association carries social consequences, this feature significantly reduces the risk of stigma for users.



/start 17:27

Привіт! Я тут, щоби вислухати і підтримати тебе 💛.
Занотую інфо про актуальні потреби, скерую твій зворотній зв'язок про послуги необхідним людям, підберу важливу інформацію під індивідуальний запит. Почнемо? 17:27

Ця частина анкети призначена для жінок, які живуть з ВІЛ і протягом останнього року відвідували жіночу консультацію. Це про Вас? 17:27

In other contexts within the EECA region, such platforms may include WhatsApp, Viber or another messaging app with Bot API support. The selection criteria remain unchanged: prevalence within patient communities, the technical capability for anonymous participation, and data encryption.

3.2 Modular chatbot architecture

Both chatbots are built on a single architectural principle – four autonomous functional modules that can be used independently or sequentially:

SURVEY MODULE	Structured questionnaires (2-12 minutes) on service quality, barriers to access, rights violations and programme coverage. Questions are aligned with the PHC's data requirements and the GF's KPIs to ensure integration into the national M&E system.
LEGAL MODULE	A section on legal information covering rights in the context of HIV services: the right to treatment, protection against discrimination, complaint procedures, and available legal remedies. Updated by the organisation's administrator without the developer's involvement.
REFERRAL DIRECTORY	A regularly updated contact database: hotlines, legal aid, social workers, specialist medical services, civil society organisations. Structured by region and type of service.
FEEDBACK MODULE	A mechanism for submitting comments on the tool itself, reports of technical faults, or suggestions for additions. Closes the feedback loop regarding usability.

Each module functions independently: updating content in the legal module does not require any changes to the survey logic; adding a new service to the directory does not affect the structure questionnaires. This modularity is key to the tool's viability – organisations without an IT team can maintain and develop the tool themselves.

The specific content of the modules varies between organisations. PUD.UA uses a two-format survey design (quick and detailed questionnaires) with a module for documenting individual rights violations. The "Positive Women" employs a multi-module thematic architecture (separate modules for HIV, TB, viral hepatitis, STIs, pregnancy, and breastfeeding) with trauma-informed navigation logic. Details of these adaptations are presented in the relevant case studies.

3.3 Dashboard and analytics

The admin panel provides an analytical infrastructure that transforms raw user responses into organisational analytics. Four types of reports are available:

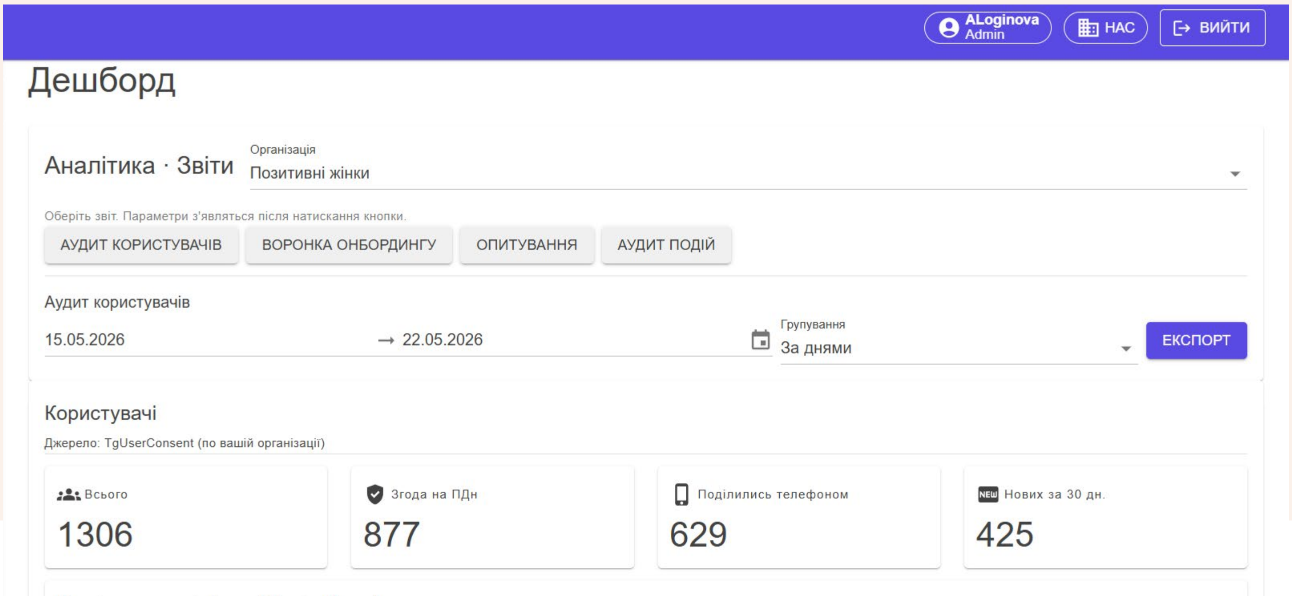
- **Funnel report.** Tracks the user's journey from the first interaction to the completion of the survey, identifying at which questions activity ceases. Used to improve the tool and the order of questions.
- **Survey report.** Provides an aggregated analysis of responses for each survey, including response distribution and average completion time.
- **User audit.** Tracks new and returning users, session duration and entry points (direct access, via referral link). Used to assess the effectiveness of engagement campaigns and reach within patient communities.
- **Dashboards.** Visualisation of key engagement metrics in real time, with the option to export to Excel for external reporting without additional data processing.

Principle: analytics without IT dependency

A key project requirement was that organisations should be able to generate and use analytics without involving external technical staff. All report generation is available to administrators via the dashboard interface. Export to Excel is built-in. Working with the dashboard does not require data science skills.

Algorithm for handling data from organisations:

- ▶ The user completes a survey in the chatbot;
- ▶ responses are automatically aggregated by subject category, geographical area and type of violation in the admin panel;
- ▶ analytical reports are generated (funnel, surveys, user audit);
- ▶ data is exported to Excel for further analysis
- ▶ an analytical report is compiled
- ▶ used for advocacy briefs and institutional reporting.



Дешборд

Аналітика · Звіти

Організація: Позитивні жінки

Оберіть звіт. Параметри з'являться після натискання кнопки.

Аудит користувачів

15.05.2026 → 22.05.2026

Групування: За днями

Користувачі

Джерело: TgUserConsent (по вашій організації)

Всього	Згода на ПДн	Поділились телефоном	Нових за 30 дн.
1306	877	629	425

Stages of data processing:

Data collection	Downloading a dataset for a specified period and topic from sources and exporting it to a file (e.g., spreadsheet format)
Initial data verification	Conducting technical verification: checking for duplicates, ensuring data is correctly entered, and identifying errors and incorrect values using available tools
Aggregation	Combining the obtained data into a single dataset for further processing
Data analysis	Identifying trends, formulating hypotheses, and defining key indicators and metrics
Full proofreading	Detailed verification and review of data, refinement and consolidation of identified trends
Compilation of a comprehensive report	Preparation of a detailed report using templates covering a wide range of issues for internal use
Preparation of summarised materials	Creation of abridged versions of reports for different audiences: inclusion of key findings and recommendations, formatting in accordance with requirements, preparation of presentation materials

What does this mean in practice?

Behind these technical descriptions lies the concrete, day-to-day experience of the team and the organizations involved. Regional coordinators can open the admin panel in just a few minutes to see how many respondents have completed the survey over the past week, which healthcare facilities have collected the most responses, and which questions respondents are getting stuck on.

An analyst generates a funnel, which shows that 15% of respondents stop answering after a certain thematic block – this is a signal either of an incorrectly worded question or of a highly sensitive topic that requires a revised approach. The program manager exports data for a single region into Excel, compares it with other metrics, and formulates key points to present at next week's Coordination Council meeting.

> “What worries me most is keeping my status a secret. At public hospitals, there are endless questions, suspicions, and inquiries from doctors: instead of getting help, support, or treatment there, I just go to a pharmacy to consult with a pharmacist or to a private lab. I can’t tell my primary care doctor about my status – I know in advance that the attitude will be terrible.
> Another scary thing for me is that after getting a discharge summary from the maternity ward, it’s hard to find a pediatrician to register the baby. The situation with infant formula is also disheartening: I have to buy it myself, even though the government is supposed to provide it.”
>
> **Olena, Cherkasy, woman living with HIV, married and raising a 2-year-old daughter**

All of this happens without involving programmers, without needing to contact technical support, and without any waiting. This is what it means to put the principle of technical independence into practice: the organisation has complete control over its data from the moment it is collected right through to the presentation of the results.

The user-friendly nature of the admin panel is a deliberate design choice, not a side effect. The interface is designed so that anyone who knows how to use email and Excel can use all the panel’s features without any additional training. All reports are generated with the click of a button or two. Filters by region, time period and survey topic are available via drop-down menus. Data export to Excel is built-in and requires no intermediate processing steps. Updates to content – the legal module, service directory, and question wording is carried out by the organisation’s administrator via the dashboard interface, without involving a developer and without affecting other modules of the tool.

For organisations that previously relied on external IT consultants for even the simplest analytical tasks, this level of autonomy is transformative. It means that decisions on what data to analyse, when to generate a report and in what format to present the results are made by the organisation’s team – rather than a technical contractor, whose schedule does not always align with the needs of the advocacy process.

Principle: analytics without reliance on IT. A key project requirement was that organisations should be able to generate and utilise analytics without the need for external technical staff. All report generation is accessible to administrators via the dashboard interface. Export to Excel is built-in. Using the dashboard does not require data science skills.

3.4 Data security and anonymity

Data processing is carried out on a voluntary basis and under user control. A phone number is not required to use the bot. All surveys can be completed anonymously. Users can delete their data via the bot's interface. Data is de-identified prior to aggregation and stored in an encrypted infrastructure in accordance with current Ukrainian legislation on personal data protection.

For key population groups facing legal risks, stigma and discrimination, these safeguards are prerequisites for meaningful participation. The survey completion rate of around 80%, recorded during the pilot phase, indicates that users perceived the tool as safe and accessible.

3.5 Ethics and consent

Participation in the survey is completely anonymous: the system does not collect telephone numbers, names or other personal identifiers of respondents. Data is stored in encrypted form in accordance with the requirements of current Ukrainian legislation on the protection of personal data. Respondents retain control over the amount of information they provide and may withdraw their participation at any stage. The average time taken to complete the questionnaire is 2–3 minutes, which was a deliberate design choice aimed at minimising the burden on participants and lowering the barrier to entry for members of the patient community with limited time.

3.6 Integration with the Central Database of PHC

One of the project's defining achievements – and the most significant institutional innovation – was the integration of CLM data generated by chatbots into the CBD of PHC. The CLM data from PUD.UA and "Positive Women" were the first community-generated datasets to be integrated into this national system.

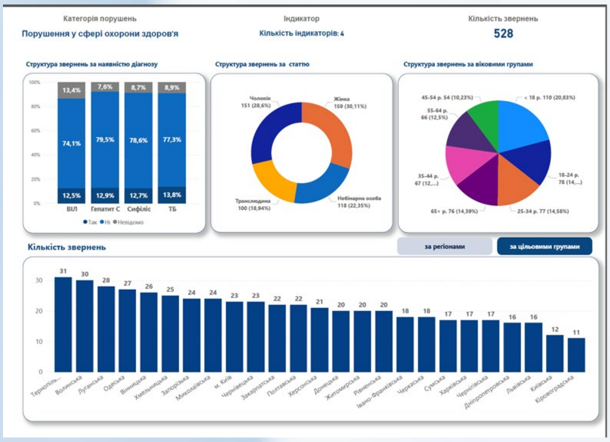
The **Central Database** is a technical solution developed by the Public Health Centre and is essentially a national platform for aggregating and analysing data on violations of the rights of key population groups, barriers to accessing services, and the quality of programme interventions. The CDB aims to consolidate data from various sources in particular, systems for collecting data on rights violations and CLM systems – into a single analytical ecosystem.

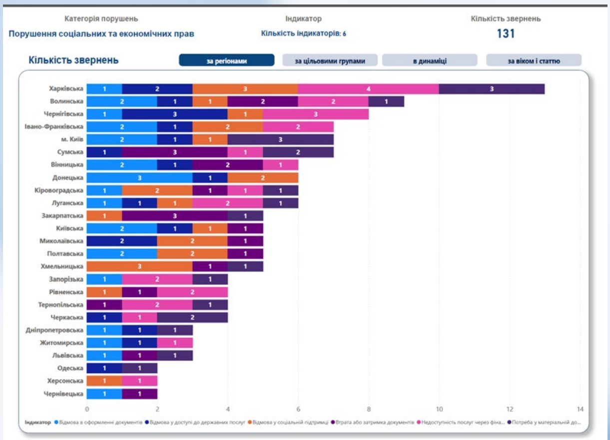
Key functions of the database:

- ▶ Aggregation – combining data from all sources into a single system;
- ▶ AI analytics – identifying patterns of violations and forecasting;
- ▶ operational dashboards – real-time visualisation;
- ▶ alert system – automatic notification of critical incidents;
- ▶ standardisation – uniform protocols and data formats for all participants.

The integration required:
(1) alignment of questionnaire structures and data fields with the technical specifications of the Central Database;
(2) the development of a data exchange protocol agreed with the technical teams of PHC;
(3) consistent advocacy by the HAC to support the PHC's involvement despite significant institutional pressure during wartime.

Following the integration, a draft Memorandum of Cooperation between the PHC and community organisations was developed, establishing standardised data exchange procedures and creating a replicable regulatory template for the future integration of other organisations.





WHY THIS MATTERS

Integration into the central database means that community-generated data enters the very same information system that the CSO uses for programme planning, resource allocation and donor reporting. For the first time, CLM data can influence these processes not only through advocacy, but through institutional data flows. This is operationalisation "the experiences of patients and service users in decision-making' at a systemic level.

4. IMPLEMENTATION SPECIFICS

This section describes the sequence of steps for implementing a digital CLM toolkit based on a messaging platform in new organisations in Ukraine or other EECA countries (or those with a similar context).

4.1 Technical adaptation and resource provision

Before proceeding to the step-by-step implementation, a number of technical and resource-related prerequisites must be met:

Selecting partner organisations from key communities. Before taking any technical steps, it is necessary to determine which community organisations will act as CLM implementers. The project's experience has shown that the success of implementation depends directly on two characteristics of the partner organisation.

- Firstly, **the organisation must meet the criteria for organisational capacity:** the presence of an established team with experience in programme work, analytical skills (at least basic), experience of interacting with state institutions and coordination platforms, and the ability to document results and formulate advocacy arguments. An organisation that lacks these basic competencies risks turning a digital tool into a technical superstructure without any substantive content.
- Secondly, **the organisation must have its own infrastructure** – a regional network (local coordinators, leaders and representatives), channels of trust within the community, and access to the target audience. It is this infrastructure that provides something no digital tool can replace: face-to-face contact, a recommendation from a trusted individual, and support whilst completing the survey. In both documented case studies, the highest coverage rates were observed in regions with the most developed network of coordinators – not those with the best internet connection or the highest digital literacy.

Work on building partners' capacity. Even where the basic conditions are in place, organisations need targeted support to implement digital CLM tool. This support is not limited to initial training on how to use a specific digital solution.

The project's experience has identified a need for capacity building in several areas: training in the use of the admin panel and analytical functions; developing skills in data interpretation and the preparation of analytical outputs; developing communication skills for presenting results at various levels (from regional coordination councils to national platforms); mentoring on institutional integration processes (harmonising data exchange formats, drafting memoranda).

This process is ongoing throughout the entire implementation cycle, rather than a one-off event. Access to mentoring and technical support is particularly critical for organisations with no prior experience of implementing such tools.

In parallel with identifying partners and developing their capacity, it is necessary to ensure a number of technical and resource-related prerequisites:

1. **Selection of a messaging platform.** Assess the penetration of various messaging apps within the target community. Criteria: prevalence among the target group, availability of a Bot API, possibility of anonymous participation, data encryption.

2. **Engaging a technical developer.** Formulate the technical specifications: modular questionnaire architecture, admin panel with analytics (data export, filters, reports), regional labelling, export to Excel. Ensure administrative control is transferred to the owning organisation (content management independent of the developer).

3. **Ensuring compliance with data protection standards.** Anonymity of participation (no collection of phone numbers or personal data), encrypted storage, compliance with national legislation on personal data protection. In the context of CLM, this is a prerequisite for trust and participation among patient communities.

4. **Funding the technical component.** Identify the source of funding for development (sub-grant, donor project, own resources). Budget for: initial development, iterative refinement following the pilot, and technical support during the scaling phase.

5. **Planning integration with government systems.** As early as the technical design stage, the data format should be agreed with the potential receiving system (in the case of Ukraine, the CBD). Prior agreement on data fields and the exchange format significantly simplifies subsequent integration. This is the “two products, one system’ principle, where the chatbot and the database are an interconnected infrastructure from the very start.

4.2 Schematic sequence of actions

1 Analysis of readiness and objectives

- ▶ Identify priority issues and monitoring topics
- ▶ Assess the level of digital access and awareness of the selected messaging app within the target group
- ▶ Identify key institutional partners (equivalent to the Public Health Centre, Department of Health, NGOs)
- ▶ Secure funding and allocate 1–2 process administrators

2 Develop a tool

- ▶ Involve community of the and regional coordinators to help formulate questionnaire questions
- ▶ Develop a modular architecture for the chatbot (questionnaire format to be determined by community needs)
- ▶ Set up regional labelling and the admin panel
- ▶ Conduct internal technical testing and document errors

3 Pilot

- ▶ Select 3–5 pilot regions with an existing network of leaders
- ▶ To organise training for regional coordinatorsl (administration + working with respondents)
- ▶ Launch a pilot, collect feedback, refine questionnaires
- ▶ Determine the data flow logic and the quality of the exports

4 Scaling and engagement

- ▶ Expand reach through available community communication channels
- ▶ If necessary, agree on the placement of QR codes with healthcare facilities
- ▶ Recruit additional coordinators in new regions
- ▶ Monitor indicators completion of via the admin panel

5 Analysis and advocacy

- ▶ Generate quarterly analytical reports (regional breakdown, typology of violations)
- ▶ Prepare analytical reports and advocacy briefs
- ▶ Present findings at coordination councils, working groups and the CCM
- ▶ Record the reaction of and changes in practice/policy

6 Institutionalisation and sustainability

- ▶ Integrate CLM into the organisation’s operational and advocacy plans
- ▶ To conclude an agreement on exchange data with a public health authority
- ▶ Transfer funding for CLM operations to a sustainable mechanism (GF or other)

Note on adaptations

The diagram provided is a basic outline. Each organisation has adapted it to suit the specific needs of their community and operational model. For example, “Positive Women” added a separate step to coordinate with healthcare facilities for the placement of QR materials, while PUD.UA large community events (the 9th National Forum of People Living with HIV) as a scaling channel. These adaptations are described in the relevant case studies.

5. CONCLUSIONS ON THE CREATION AND IMPLEMENTATION OF A CLM TOOL FOR PATIENT COMMUNITIES

5.1 What went well

The first phase of the initiative’s implementation fully confirmed the hypothesis that a digital CLM based on messaging apps can function as a genuinely accessible tool for engaging patient communities. In this sense, chatbots have become not merely a technical solution, but an extension of existing community ties.

The experience of both organisations described in this article points to several success factors that are systemic in nature and not coincidental:

- **A low-threshold digital tool as a condition for participation, rather than a convenience.** In both cases, the high response rate and completion rate of the surveys (around 80%) are due not to aggressive outreach, but to design features: anonymity, minimal completion time (2–3 minutes), no registration required, and the familiar Telegram interface. For communities facing stigma, criminalisation and mistrust of formal systems, these characteristics are not optional extras, but fundamental prerequisites for any form of participation.
- **The co-creation model ensured relevance and acceptance.** The involvement of community representatives in the design of the questionnaires – from formulating the questions to determining the flow of the survey and identifying sensitive topics – made the tools feel “their own’ to the target audience.

> “When receiving medical care, I always have one thought: to get my treatment or whatever service quickly – and get out of the hospital straight away. It’s not so much about bad treatment, but more about the discomfort caused by the responses I get to my complaints or health questions: “What did you expect? You have HIV and chronic conditions.’ But I want a specific answer on what I should do – not a humiliating and demeaning reminder of my own daily struggle for health.”
>
> **Olena, 41, Mykolaiv, woman living with HIV and raising her daughter**

- **Digital tools and community infrastructure as a single system.** A chatbot on its own does not ensure either sufficient reach or data quality. The result is achieved by combining the digital tool with the organisations’ living infrastructure: regional coordinators, community leaders, offline events, informal newsletters, QR codes and support for respondents whilst they were completing the survey. Institutional channels (official letters, information posted on websites) played a supporting role; the main outreach was provided by people working on a peer-to-peer basis who have trusting relationships with the community. Digitalisation does not replace the role of people – on the contrary, it makes strong networks more effective. For replication, this means that without an established community infrastructure, even a perfectly designed tool will not generate sufficient data for evidence-based advocacy.
- **Built-in analytics has closed the loop from data collection to advocacy.** An admin panel featuring dashboards, filters, Excel export and regional disaggregation has enabled organisations to independently complete the full analytical cycle. This has fundamentally changed the dynamics: data is no longer a “dead weight’ but has become a practical advocacy tool.
- **Integration with the Public Health Centre’s CDB has institutionalised the experiences of patients and service users.** The shift from “data-driven’ advocacy to the integration of this data into the national information system has transformed the nature of the dialogue between communities and the state. CLM data is fed into the very same platform that the CCH uses for programme planning – a significant leap forward compared to previous practices – and for the first time becomes part of the analytical database used to track progress against cascade indicators and make decisions on resource allocation between programme interventions.

5.2 What did not work or required significantly more resources

- **Delays in tool development.** In both cases, the technical development of the chatbots took longer than planned, which pushed back the deadlines for related activities. This is a common pattern in software development that should be factored into project planning as a technical buffer: at least 30–50% of the originally planned development time.
- **The complexity of institutional integration.** Formalising data exchange with the Public Health Centre required several rounds of negotiations, the agreement of indicators, the refinement of datasets, and the drafting of memoranda. This process took considerably longer than anticipated and required ongoing coordination support from the HAC. For organisations planning to replicate this work, it is important to understand that institutional integration is a separate workflow with its own time and resource requirements.
- **The diversity of data sources during the transition phase.** The PUD.UA team faced the problem of using several data collection tools simultaneously (chatbot, Google Forms, SurveyMonkey), which complicated data analysis and consolidation. The strategic decision to switch to a single primary tool significantly simplified the processes: however, the transition period required separate efforts.
- **Underestimation of the resources required for the scaling phase.** As the volume of data and geographical coverage grew, the tool evolved from a pilot solution into a key component of the organisation’s operational activities. This required significantly more resources than had been anticipated during the planning stage, in terms of both funding and staffing.
- **Varying levels of organisational readiness among partners.** Even if an organisation has strong community ties, this does not always mean it immediately possesses sufficient analytical, technical or advocacy capacity for the full CLM cycle. Some of the work required more mentoring than might have appeared at the outset.
- **The difficulty of striking a balance between the minimum length of the questionnaire and the depth of information.** Short surveys are easier to complete and place less of a burden on respondents, but do not always provide enough detail for in-depth analysis. Long questionnaires provide more content but increase the risk of non-completion. Therefore, a flexible approach is needed: short, regular questionnaires to monitor trends and detailed modules for specific topics or periodic in-depth analyses.
- **The burden on organisations.** CLM requires time not only for data collection, but also for administration, data cleansing, analysis, preparing materials, communicating with stakeholders, documenting results and updating tools. This needs to be acknowledged honestly and budgeted for accordingly. Otherwise, CLM quickly becomes “just another activity’ that relies on the enthusiasm of a few individuals.
- **Consistency of technical support.** Even if the admin panel is user-friendly, the tool still requires technical support: updates, bug fixes, adaptation to new requirements, security maintenance, and potential integration with other systems. This is not a one-off purchase, but an infrastructure that requires maintenance.

5.3 What to consider when scaling up in Ukraine

To scale up in Ukraine, the first step is to select partners not only based on their thematic relevance to the patient community, but also on their readiness to manage processes. The organisation must have the trust of the community, a regional or thematic network, responsible people, basic analytical capacity, and a willingness to use data for advocacy.

- **A networks of trust is not built from scratch.** The success of both cases is largely due to the organisations' long-standing presence in their communities, well-developed networks of coordinators, and an established level of trust. For organisations with less developed networks, a preliminary stage of strengthening the community infrastructure is necessary – otherwise, the digital tool will have no channel for engaging respondents.
- **Technical support remains essential.** Even with existing templates and experience, new organisations will require technical support during the stages of adapting the tool, training the team and integrating with the central database. The model provides for the role of a technical partner (which was fulfilled by HAC in this project), and this role must be resourced.
- **The existing institutional framework paves the way.** The presence of the CBD of Community Organisations, CLM working groups under the Social Solidarity Movement, Coordination Councils at regional level, and a generally established institutional environment for CLM in Ukraine means that new organisations do not have to start from scratch in building the institutional landscape – they can simply join an already established system. The draft Memorandum of Cooperation between the PHC and community organisations could serve as a regulatory template for new integrations.
- **Adapting questionnaires is essential, not merely advisable.** Each patient community has its own specific barriers, terminology, sensitive issues and patterns of interaction with the healthcare system. Using questionnaires without adapting them not only reduces data quality but may also undermine the community's trust in the tool.

> "They wouldn't let me have my medication – in other words, they effectively left me without treatment. It's vital for me, but no one took my basic need into account. It causes intense fear and a feeling that nobody needs you. Surely this shouldn't be happening?!"
>
> **Tetyana, 37, Mykolaiv region, OST patient**

5.4 What to consider when scaling up outside Ukraine

For organisations in EECA countries and other regions with a similar context (Kyrgyzstan, Kazakhstan, Moldova, Central Asian countries), the architecture is adapted, but the context differs significantly.

- **The choice of messenger is determined by the community, not the developer.** In each country, a different messenger dominates among key population groups. The selection criteria – prevalence within the patient community, availability of a Bot API, the option for anonymous participation, and encryption – remain unchanged, but the specific platform may differ (WhatsApp, Viber, or even local messengers).
- **The institutional landscape requires separate analysis.** The Ukrainian model is built on the existence of specific institutions (Public Health Centres, Central Databases, Social Services, Coordination Councils) and their readiness for partnership. In other countries, equivalents of these structures may be absent, have a different mandate, or a different level of openness to communities. Planning for integration should begin with mapping the institutional landscape and identifying potential "entry points' for CLM data into government systems.
- **The legal environment regarding data protection varies.** The model is based on Ukrainian legislation on the protection of personal data. In different jurisdictions, requirements may be stricter or more lenient, which affects the architecture of data collection and storage.
- **Levels of digital literacy and internet access vary.** In frontline regions of Ukraine, unstable connections have already been identified as a barrier. In rural regions of Central Asia, this challenge may be significantly more acute and require hybrid solutions (online and offline collection followed by synchronisation).
- **Linguistic and cultural adaptation goes beyond mere translation.** Translating questionnaires is not enough – cultural adaptation of wording is required, taking into account local taboos, the specifics of medical terminology and models of community engagement.
- **The technical partnership model is replicable.** The role of the HAC in this project – acting as a technical partner without leading the monitoring process – is structurally replicable: each country requires a technical partner to oversee development, training and coordination with government systems, whilst ensuring that ownership and management of the process remain with community-based organisations.

5.5 Key conclusions

The documented experience confirms several points that are relevant beyond the specific case studies.

- CLM functions as a tool for systemic change only when **three conditions are met simultaneously: a low-threshold and secure data collection tool, analytical autonomy for organisations, and an institutional channel for integrating data into decision-making processes.** The absence of any one of these conditions does not merely reduce the quality of monitoring – it makes it impossible to translate identified gaps in the service cascade into concrete policy adjustments.
- Digital tools based on messaging apps are a powerful but insufficient solution. Their **effectiveness depends directly on the availability of community infrastructure** – coordinators, networks of trust, advocacy experience – which ensures the collection, interpretation and use of data. Technology enhances the patient and service user experience, but in no way replaces it.
- **The integration of CLM data into government systems is an achievable goal, but it requires significant investment in terms of time, resources and sustained advocacy work.** The project's experience demonstrates that institutional readiness is not a given – it is the result of targeted efforts, and support for these efforts must be factored into resource planning.

The model described in this document is not a finished product – it is the result of the first full cycle, which has identified both achievements and limitations. Subsequent cycles of work in this area should take into account the lessons learnt, expand coverage to new communities and deepen integration with government systems.

PART B. DESCRIPTION OF BEST PRACTICES

CASE 1. CHATBOT FOR THE DATA COLLECTION INITIATIVE TARGETING PEOPLE WHO HAVE EXPERIENCE OF USING PSYCHOACTIVE SUBSTANCES CO CF PUD.UA

Geography: Ukraine (nationwide coverage; pilot in 5 regions)

CLM model: digital monitoring via the @volna_ua_bot chatbot on Telegram

Target group: people with experience of using psychoactive substances

Implementation period: June 2025 – January 2026 (pilot phase: November 2025 – January 2026)

Scale: 1,400 surveys across 24 regions, 24 trained regional coordinators

Case background: This case study was prepared based on interviews regarding the implementation of a chatbot and an assessment of this initiative with representatives of PUD.UA as well as on the organization's program and analytical reports, which were compiled using CLM data for internal use in developing advocacy activities. The context and specifics of the issue are reflected in accordance with the materials from the National Strategic Dialogue presentation (March 2026).

1. Community and organisational context

This practice is implemented by PUD.UA – a national network of people with experience of using psychoactive substances. They face systemic barriers to accessing OST, ART and harm reduction services. These barriers have been exacerbated by Russia's armed aggression: disruptions to service provision due to the relocation of OST patients, the forced discontinuation of OST during mobilisation, discrimination in healthcare facilities, the lack of OST in places of detention, and so on.

The scale of the problem is confirmed by data from the National Strategic Dialogue (March 2026): a 42% decline in HIV testing rates among PLHIV in 2025 (against a backdrop of rising overall testing coverage), poor integration of HIV, TB, viral hepatitis and OST services, and high levels of stigma in healthcare settings. These figures are not merely coverage indicators: they mean that PLHIV are systematically lost at the first stage of the cascade, even before starting treatment, and without a tool that captures the reasons for this at the level of people's experiences, the system responds to this too late or not at all. A cluster analysis for 2021–2025 (11,956 participants) identified new risk groups not reached by traditional programmes: an increase in the use of stimulants and new psychoactive substances, sexualised drug use (35% of respondents), and spiking (18.2% had experienced this, with the highest risk among those under 20).

In previous years, the PWID community had experience of monitoring services, but lacked the framework to turn monitoring data into a tool for advocacy. Data was collected haphazardly, without standardisation; monitoring was limited to the topics of substitution therapy or school-based programmes, whilst the community's needs are much broader. There was a lack of analytical capacity to transform the data into advocacy arguments. The state M&E system required a structured format to incorporate CLM data, but this did not exist.

2. MECHANICS OF IMPLEMENTING THE CLM TOOL

2.1 What was monitored and why

The key group targeted by CLM is people with experience of using psychoactive substances and cross-groups engaged through existing community networks and peer-to-peer self-organisations.

The CLM aims to: investigate access to substitution therapy, antiretroviral therapy and sexual and reproductive health services; document rights violations (including the forced discontinuation of substitution therapy during mobilisation and in prisons); identify regional gaps in service provision; and build an evidence base for advocacy. Priority topics are therefore: HIV, viral hepatitis, TB, OST (particularly in prisons and frontline regions), SH, and rights violations.

How the tool is structured: dual-format design. Previously, the organisation used Google Forms with a single long questionnaire covering all topics. The switch to two formats – "Detailed service assessment' (1,008 respondents) and "Quick service assessment' (392 respondents) – was driven by simple logic: lengthy questionnaires with 50–60 questions are exhausting. Short questionnaires allow for the rapid collection of information; detailed ones provide a deeper analysis. Both formats are easy to complete and can be filled in fairly quickly.

2.2 How respondents were recruited: trust as a channel

The key difference in this case study is the reliance on informal channels of trust rather than institutional ones. Official communications via partner organisations and healthcare facilities played a supporting role, whilst the main outreach was achieved through Viber messages sent via informal groups, targeted letters from initiative group leaders, and flyers with links to a chatbot. For a community with well-founded mistrust of formal institutions, this approach was used, and it ensured a high response rate to the questionnaires.

A prime example of how information about the survey was disseminated was the combination of offline and online methods: during the PWID National Forum (184 participants), 500 leaflets were distributed containing a link to the chatbot. Over the next two months, there were over 400 new enquiries via the bot. Face-to-face contact was converted into digital interaction because information about the tool came from people they trust.

The highest level of engagement was recorded in the Dnipropetrovsk region – not because of better internet access or higher digital literacy, but thanks to a well-developed network of regional leaders. This fact confirms the main conclusion: the key factor is not the communication channels, but the presence of trusted intermediaries.

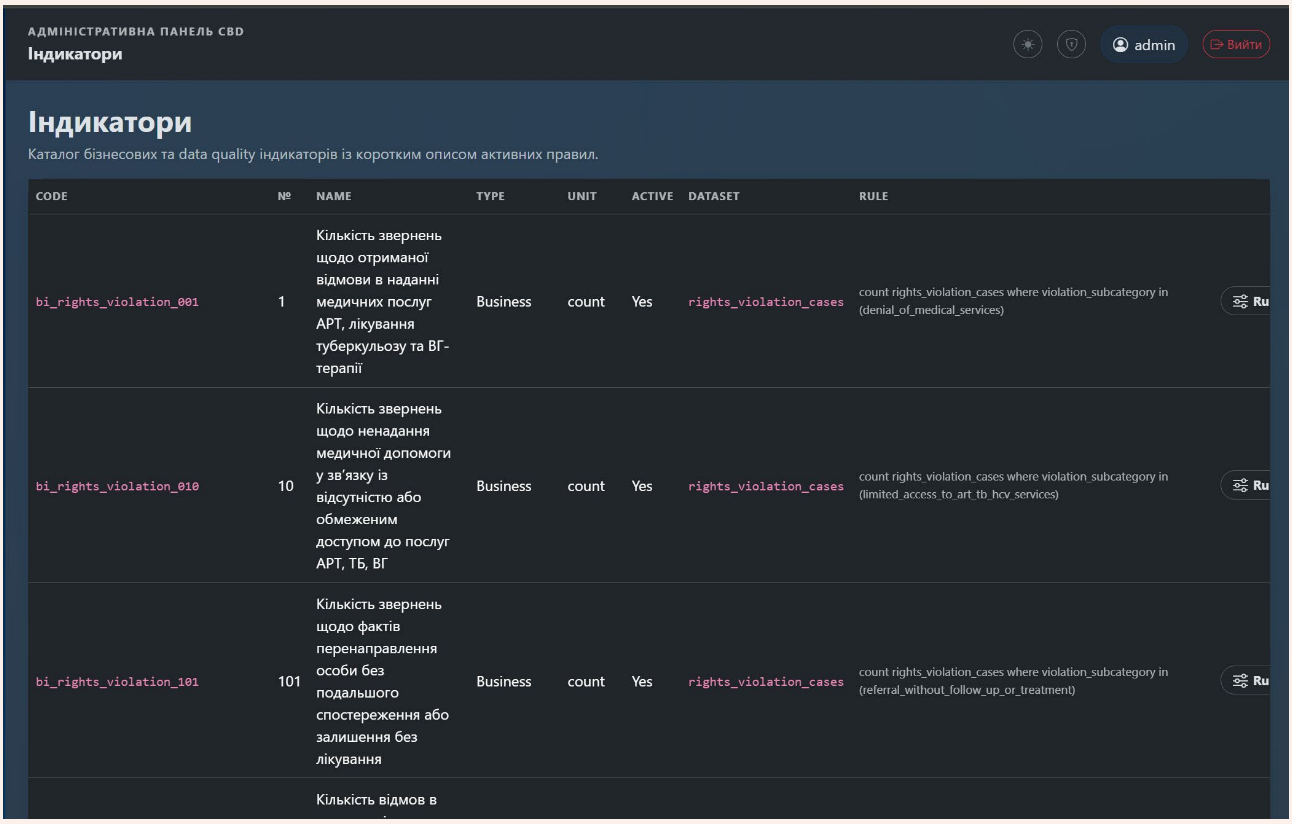
Surveys were conducted by community members independently or with the assistance of 24 regional coordinators. Participation was anonymous: the system does not collect personal identifiers, except in cases where respondents themselves wished to leave their contact details to receive support.

> "Apart from prescribing medication, the doctor shows virtually no interest in my treatment or my health in general. If you want to change the dose, they make you come in every day until they decide for themselves. It feels less like help and more like control. Because of this, I lose the desire to seek help"
>
> **Serhiy, 41, Kharkiv region, OST patient**

2.3 Integration with the database: specifics of the experience

The main challenge of integration was the heterogeneity of data sources: a chatbot, Google Forms and SurveyMonkey – each with its own logic and structure. This led to a strategic decision: to switch to a single primary data collection tool – the chatbot. The switch significantly simplified analysis and standardised the input data.

A key outcome was the expansion of the database itself. Following the data mapping exercise, it became clear that the community's actual needs extended far beyond the initial list of indicators. The dataset was supplemented with indicators on overdoses, drug-related deaths, access to detoxification and rehabilitation, compulsory treatment for drug dependence, and barriers to prevention programmes.



Індикатори

Каталог бізнесових та data quality індикаторів із коротким описом активних правил.

CODE	№	NAME	TYPE	UNIT	ACTIVE	DATASET	RULE
bi_rights_violation_001	1	Кількість звернень щодо отриманої відмови в наданні медичних послуг АРТ, лікування туберкульозу та ВГ-терапії	Business	count	Yes	rights_violation_cases	count rights_violation_cases where violation_subcategory in (denial_of_medical_services)
bi_rights_violation_010	10	Кількість звернень щодо ненадання медичної допомоги у зв'язку із відсутністю або обмеженим доступом до послуг АРТ, ТБ, ВГ	Business	count	Yes	rights_violation_cases	count rights_violation_cases where violation_subcategory in (limited_access_to_art_tb_hcv_services)
bi_rights_violation_101	101	Кількість звернень щодо фактів перенаправлення особи без подальшого спостереження або залишення без лікування	Business	count	Yes	rights_violation_cases	count rights_violation_cases where violation_subcategory in (referral_without_follow_up_or_treatment)
		Кількість відмов в					

3. RESULTS ACHIEVED

3.1 What the monitoring revealed

CLM identified barriers that the community was aware of from experience but lacked an evidence base to advocate against. Clients are forced to call to confirm the availability of OST services – the very fact that a call is required is a barrier for the most vulnerable. A reduction in OST centres has been recorded in several regions. OST is unavailable in small towns: people are forced to travel to the city. The forced discontinuation of OST during mobilisation has been documented as a systemic violation, rather than an isolated incident. In prisons, access to OST remains minimal or non-existent.

Regional disaggregation revealed specific gaps: a lack of secondary school services in the Rivne and Volyn regions, disruptions in the Chernihiv region, and poor coverage in the Kyiv region. The module for documenting violations made it possible to distinguish systemic violations from isolated incidents – which is crucial for the quality of the advocacy argument.

3.2 What has changed thanks to the data

The documented CLM data led to specific institutional responses:

At the national policy level: The Ministry of Defence has issued an official letter guaranteeing the continuity of substitution therapy during mobilisation and clarifying that individuals undergoing substitution therapy are exempt from conscription. For people on OST programmes, this means the threat of forced interruption of treatment has been removed. A proposal for amendments to Ministry of Health Order No. 200 – the key document regulating the organisation of OST in Ukraine – has been submitted to the PHC to address the issue of treatment continuity under martial law.

At regional level: OST clinics have been opened in prisons in the Vinnytsia and Odesa regions. For prisoners with opioid dependence, this is the difference between controlled treatment and forced discontinuation of treatment.

At the level of institutional relations: a regular dialogue between the Public Health Centre and PUD.UA has been formalised, and CLM data has been integrated into the central database. The state has recognised the organisation as an equal partner in data generation within the context of the national response to HIV/TB.

3.3 What has changed within the organisation itself

This approach has transformed not only what the organisation does, but also how it does it. The network of 24 regional coordinators has evolved into a decentralised system for data collection and monitoring. Each coordinator fulfils a dual role: welcoming respondents and overseeing monitoring at the local level. Community members are driving the process. The organisation has also transitioned to a single monitoring platform and carries out the full analytical cycle in-house – from data collection to the final report – integrating CLM data with indicators from other interventions.

The data is systematically transformed into advocacy materials: briefings, presentations and talking points for dialogue with institutions – ranging from the Ministry of Defence to the Ministry of Health and the Public Health Centre (PHC). CLM is integrated into financial planning within Global Fund projects: monitoring is embedded in the operational model, rather than existing as a separate project with an uncertain future.

4. LESSONS LEARNT AND RECOMMENDATIONS

This section has been prepared based on information provided by the organisation during technical interviews, as well as data from the programme report.

4.1 The formula for success: trust at every level

The common denominator of everything that worked was trust. The tool did not intimidate respondents: it was anonymous, brief, and delivered via a familiar messaging app. Distribution channels were built on trust: peer-to-peer coordinators, informal mailings, and personal recommendations. The team gained autonomy thanks to the admin panel – and trusted this too, as the tool operated without external dependencies.

At the organisational level, there is an extensive network comprising 24 coordinators and 5 resource centres, as well as long-standing trust within the community. At the partnership level, the Public Health Centre has recognised CLM data as a basis for shaping responses to HIV/TB, whilst the Health Action Coalition has provided coordination support during the complex stages of institutional negotiations. At the technical level – a chatbot featuring a modular system with regional tagging and an admin panel, as well as respondents' prior experience of participating in surveys via chatbots (76% had already used bots on Telegram).

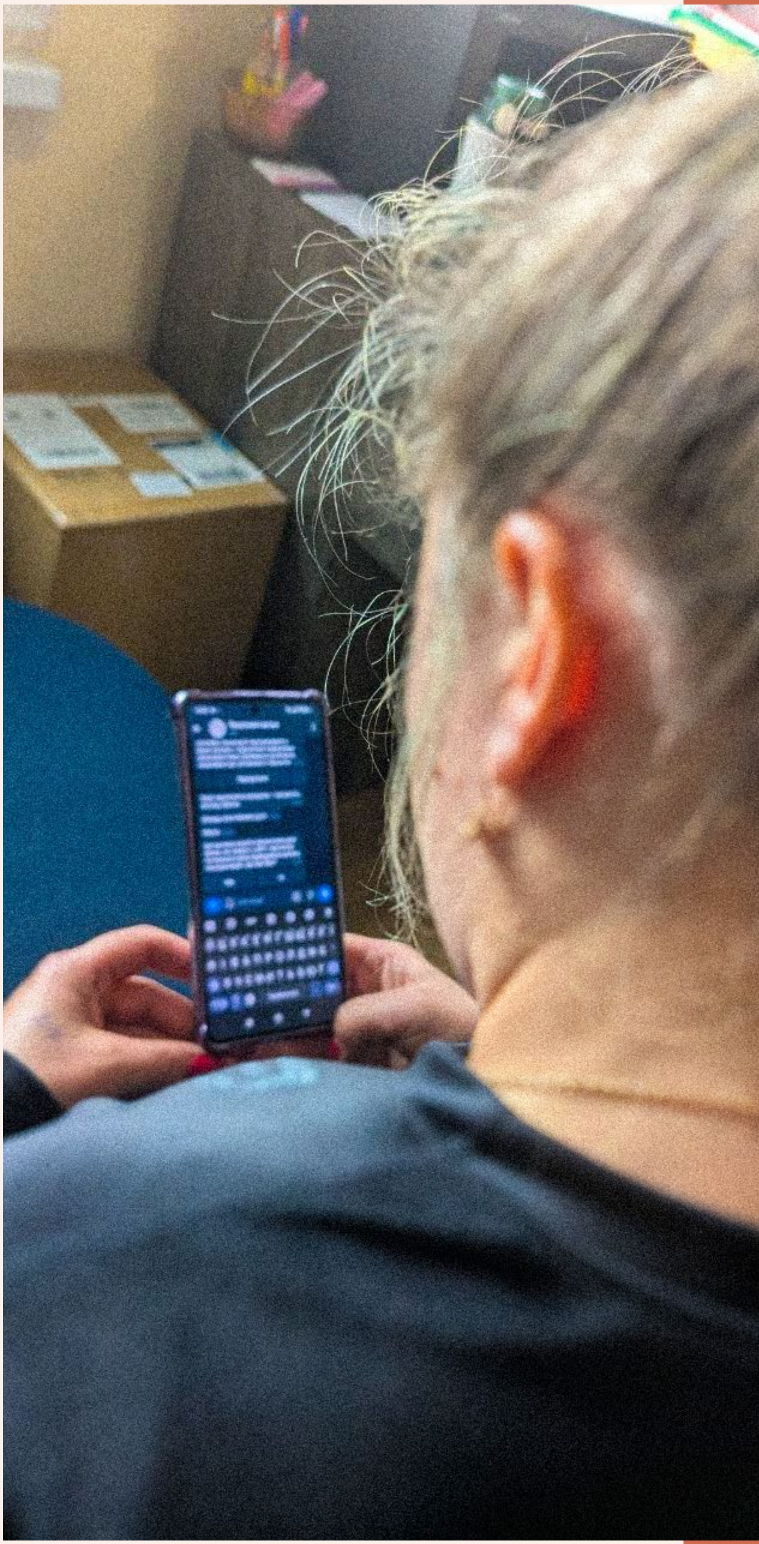
> "I was stopped in the street and forcibly thrown into a car, then taken to the TCC. Nobody explained anything; they were rude and arrogant. I felt completely defenceless. Since then, I've been afraid to go out on the street – let alone visit OST centres or take part in substitution therapy programmes."
>
> **Maksym, 39, Kyiv, OST client**

4.2 Challenges and limitations, and why it matters

External constraints: unstable internet in frontline areas affected data completeness, and uneven digital literacy necessitated individual support for some respondents. These factors cannot be addressed internally but must be factored into resource planning.

Scaling challenges: difficulties with data synchronisation arose during the expansion process – infrastructure upgrades must precede scaling, rather than merely reacting to it. Resources for system support were underestimated: the chatbot evolved from a pilot solution into a key piece of infrastructure, the system-wide implementation and support of which requires stable funding.

Process challenges: delays in tool development disrupted related activities – hence the need for a technical buffer in project plans. Formalising data exchange with the Central Government Agency took significantly longer than anticipated – institutional integration must be planned as a separate workflow.



4.3 Vision for the next 2–3 years

The Telegram bot remains the primary platform for collecting CLM data. To reach respondents who are not using digital channels, we plan to add a Google Form with an identical set of questions – not as a parallel tool, but as an extension of the existing system, ensuring data compatibility. A promising area is the implementation of AI analytics for the automatic generation of regional reports.

4.4 Recommendations for replication

- The tool should be designed with a priority on minimising the burden on the user – for communities with high levels of distrust towards formal systems, this is a basic condition for participation, rather than a matter of convenience.
- The tool's dissemination should be built on networks of trust. Peer-to-peer coordinators and informal channels are significantly more effective than institutional mechanisms.
- The analytical infrastructure – regional disaggregation, automated reporting, funnel monitoring – must be built in at the development stage, rather than added later.
- Resource planning must take into account the success scenario: an effective tool inevitably becomes part of the infrastructure, requiring stable funding and a dedicated, trained team.
- Support for implementers must be continuous throughout the entire cycle. Institutional integration processes consistently take longer than anticipated and must be planned for as a separate resource.

> "Do you know what motivates me to fight for my rights? First and foremost, it's the realization of how important my own health is and the need for regular treatment, but even more so – the desire to live life to the fullest. Especially since I'm responsible not only for myself but also for my child. At the same time, the biggest demotivator is the lack of confidence in the future. I'm constantly worried about the availability of treatment and the stability of medication supplies. There's a fear that at some point, there might be no more medicine deliveries. And even when medications are initially dispensed for a month and then for several months in advance, the anxiety remains – especially in wartime."
>
> **Iryna, 34, Kremenchuk, woman living with HIV, mother of a 13-year-old son**

CASE 2. CHATBOT FOR COLLECTING DATA FROM WOMEN LIVING WITH HIV (CO “POSITIVE WOMEN”)

Geography: Ukraine (5 pilot regions: Lviv, Mykolaiv, Poltava, Zaporizhzhia, Cherkasy; expanded to national level by the end of 2025)

CLM model: gender-sensitive digital model via the @UKRAINEpw_bot chatbot on Telegram

Target group: women living with HIV (WLHIV)

Implementation period: September 2024 – January 2026

Scale: 818 women, 60+ healthcare facilities, 1,345 completed questionnaires, a completion rate ~80%

Case background: the case was prepared based on presentations from the National Strategic Dialogue (March 2026), which outline the broader context of the issue, programme reports and internal analytical overviews based on CLM data and used in planning the organisation’s advocacy work, as well as interviews with representatives of the charitable organisation “Positive Women”, conducted to comprehensively study the organisation’s experience in implementing and using a chatbot, including lessons learnt, achievements and prospects.

1. Community and organisational context

PLHIV in Ukraine face barriers that extend far beyond HIV treatment: antenatal care and childbirth, access to SRH services, provision of infant formula for newborns of WLHIV, and confidentiality. Some of these issues have long remained invisible to the healthcare system – they were not recorded in official statistics or were treated as isolated cases rather than systemic violations.

According to the results of the CLM data assessment, as reported by the organisation during interviews, it was found that women are regularly forced to pay for services that should be free under the Medical Guarantees Programme: laboratory tests, antenatal care, childbirth, and postnatal care. In frontline areas and regions with large numbers of IDPs, women more frequently reported difficulties accessing treatment. In some cases, the lack of local registration served as grounds for refusal.

Stigma and breaches of confidentiality remain among the most sensitive issues: the disclosure of HIV status without consent, discriminatory treatment in maternity wards, and segregation when accessing healthcare services. This leads to some women avoiding healthcare facilities, discontinuing treatment or losing trust in the system. It is concerns about stigma, rather than a lack of medication, that are the most common reason why women discontinue contact with the healthcare system: fear drives them out of the cascade earlier than any logistical barrier.

Prior to the initiative, the organisation collected feedback from clients, but the process was fragmented: differing methodologies and tools made it difficult to compare data across regions. The CSC did not have a consistent mechanism for obtaining structured feedback specifically from women living with HIV. The chatbot became a tool that, for the first time, allowed these barriers to be systematically recorded and Women"s voices to be integrated into decision-making processes.

> “For the first time, I felt that my opinion was being sought. And that it matters! That this isn’t just about gathering information or feedback, but actually making a difference to the way things are”
>
> **Olena, 43, Zaporizhzhia, woman living with HIV**

2. MECHANICS OF IMPLEMENTING THE CLM TOOL

2.1 What was monitored and why

The CLM aims to monitor gender-specific barriers in HIV, TB and viral hepatitis services; documenting rights violations (confidentiality, denial of care, stigma); tracking access to medications to maintain suppression, SRH, antenatal care and pregnancy-related services; building an evidence base for regional and national advocacy.

How the tool is structured: a multi-module thematic architecture

The specific feature of the tool developed for the "Positive Women" NGO is its multi-module thematic design. The organisation has several long and short questionnaires on specific topics: access to infant formula, SRH services, antenatal care and childbirth, HIV/TB/hepatitis, and integrated services. The logic is structured as follows: separate thematic surveys offer greater flexibility than long questionnaires; they can be supplemented as new needs arise; this differentiation allows for a focus on specific issues and significantly simplifies data processing.

A key distinction is **the trauma-informed logic of transitions**: questions are phrased neutrally and ethically to avoid retraumatisation. It is this design, according to the organisation's assessment, that contributed to the high completion rate (80%) and the candour of the responses. Over 30 community members participated in the development of the questionnaires – the tool is perceived not as an external technology, but as something created by the community itself.

2.2 How respondents were recruited: a hybrid model

In addition to standard channels (intra-programme messages, the website, events), a key tool was the placement of QR codes in healthcare facilities. To facilitate the dissemination of information about the tool, the organisation sent official letters to regional health authorities in five pilot regions; in three of these, coordinators held meetings with healthcare facility management, presented the chatbot and secured support. It was not possible to track the effectiveness of the QR code channel in isolation, but in synergy with the coordinators' work, it was a driving force in attracting respondents.

Women completed the survey independently, often with the support of regional coordinators – including the provision of gadgets and the completion of surveys in the organisation's safe space. Anonymity is emphasised during every meeting with the women. The respondents' trust is built on the organisation's 13 years of work with the community, as well as recommendations from coordinators, paralegals and case managers.

At the same time, certain topics required caution: open-ended questions (region, name of the establishment) yielded partial answers that required manual analysis. Women who needed help often did not wish to leave their contact details – which made it difficult to respond to individual cases.

2.3 Data processing: division of roles

The organisation uses two approaches depending on the type of survey. For long questionnaires – a full cycle: daily data upload ▶ “cleaning’ (duplicates, incorrect answers, categorisation) ▶ communication and analysis cycle (identifying key themes in collaboration with programme specialists and analysts) ▶ preparation of advocacy materials ▶ transfer to the regional level. For short surveys, the process is simplified: after basic processing, the results are promptly transferred to the regions for ongoing advocacy.

The analytical approach is combined: quantitative (aggregation by themes, regions, indicators) is combined with qualitative (contextual interpretation, identification of advocacy priorities). Regional differences and recurring barriers are analysed separately.

> “I dream of the war ending. Of being able to live in stability, plan for the future, and feel confident about tomorrow. I also desperately hope that one day a cure will be found – and that HIV will become curable. Another challenge for me is finding work and achieving financial stability: to secure my child’s future and realise my own goals.”
>
> In difficult times, it’s the community of women that offers support. I’ve been travelling to Poltava for support groups and counselling sessions for quite some time now, and I sometimes help to run mutual support meetings. It’s important to me to feel that I’m making a difference and to have the chance to share my own experiences with others.
>
> My inner resolve also helps – to keep moving forward and never give up. As in Scarlett O’Hara’s famous line: “I’ll think about that tomorrow’
>
> **Iryna, 34, Kremenchuk, woman living with HIV, mother of a 13-year-old son**

2.4 Integration with the Central Database: specifics of the experience

The integration marked a phase of rethinking approaches. During the data mapping process, it became apparent that the needs of women in vulnerable situations extend beyond the categories originally envisaged. With the organisation’s support, indicators related to pregnancy – which were previously absent from the database – were included, along with indicators of gender-sensitive barriers. This drew attention to the fact that standard data collection systems do not always take into account Women”s specific experiences.

3. RESULTS ACHIEVED

3.1 What the monitoring revealed

CLM has identified gender-specific barriers that were either overlooked by the system or not treated as a priority. Medicines to suppress lactation and infant formula are systematically unavailable in public facilities, resulting in significant costs for women. Disruptions in the coordination of primary healthcare services, breaches of confidentiality, and discriminatory treatment in maternity hospitals were recorded.

Regional disaggregation made it possible to distinguish systemic problems from local incidents – and to select an appropriate advocacy strategy: some issues required changes at the national level, whilst others were resolved through regional mechanisms.

3.2 What has changed thanks to the data

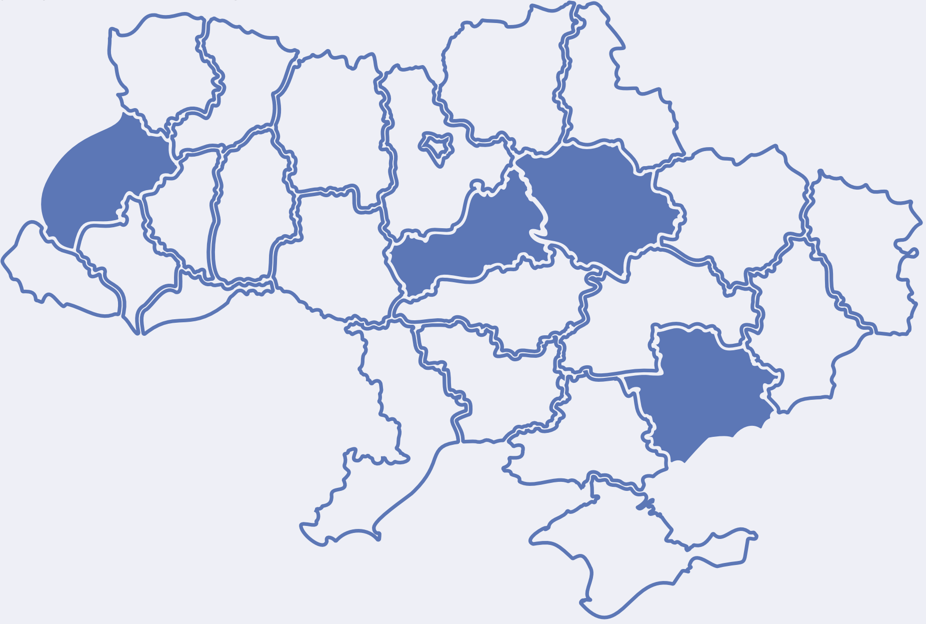
Poltava region: for the first time at regional level, a decision was taken to provide budgetary funding for lactation-suppressing drugs and infant formula for children born to women living with HIV. An issue previously viewed as the individual responsibility of women began to be seen as a matter of systemic provision.

Cherkasy Region: funding for infant formula has been allocated in three communities where such provision was previously unavailable; in the remaining communities, funding levels have increased two-to threefold. This is an example of how local data directly influences budgetary decisions.

Lviv region: data on barriers to accessing sexual and reproductive health services became a key argument for ensuring access to HPV vaccination for young women. CLM formed the basis for a review of prevention approaches.

Zaporizhzhia region: the CLM data influenced not only financial decisions, but also changes in professional practices. Since the monitoring revealed a high level of stigma – which is a direct factor in keeping women in the healthcare system and on treatment – training for healthcare workers on a non-discriminatory approach was successfully integrated into the Regional Action Plan on HIV/TB for 2026. Similar measures have also been implemented in Lviv and Mykolaiv.

National level: the development of new indicators for the Central Database relating to pregnancy and access to services has been initiated – recognising that gender-sensitive aspects must be integrated into national monitoring systems.



3.3 What has changed within the organisation

This initiative changed not only what the organization does, but also how it does it. The experience of using a chatbot, tested in five regions, was scaled up across the entire network of 24 regional coordinators – thus expanding the decentralized data collection and monitoring system to nationwide coverage. The coordinators had previously collected data and prepared materials as part of Global Fund projects, but it was specifically through this initiative that the team received mentoring support in the area of advocacy – and this reinforced the coordinators' growing confidence in engaging with regional authorities.

The chatbot has become the primary data collection tool with an integrated legal module – a tool that serves not only for monitoring but also as a service. The organisation carries out the full analytical cycle in-house, combining CLM data and indicators from other interventions into a single picture. The data is systematically transformed into advocacy products. The CLM is integrated into the financial framework of Global Fund projects: monitoring is embedded in the operational model, rather than existing as a separate project with an uncertain future.

4. LESSONS LEARNT AND RECOMMENDATIONS

This section has been prepared based on information provided by the organisation during technical interviews, as well as data from the programme report.

4.1 The formula for success: gender sensitivity as an architectural principle

For the “Positive Women”, the key word became “sensitivity’ – and this is not a decorative element, but an architectural solution. The trauma-informed design of the results obtained only influenced the quality and volume of the data: an 80% completion rate, detailed and candid responses.

The infrastructure of trust, built up over the organisation’s 13 years of work, became the foundation for working with the tool. Paralegals, case managers and coordinators with established relationships within the community proved more effective than any digital channel. Involving more than 30 women living with HIV in the development of the questionnaires turned the tool into a community asset.

The hybrid model – distribution via coordinators and QR codes in healthcare facilities – enabled us to reach beyond the existing community. The bot’s modular architecture made it possible to collect targeted data without overloading the system. Among the external factors were existing partnerships with regional authorities and Coordination Councils, which enabled data to be translated into decisions more quickly.

> “You know what’s the hardest part of my life? Keeping my job. Because it’s getting harder and harder – both mentally and physically. And the first person I think of is my daughter. I want her to have everything she needs right now, not sometime in the future…
> The support of peers and counseling at the organization really helps me not to give up. And also – to look for the positive in literally everything: that’s what I do in my “positive’ life.”
>
> **Olena, 41, Mykolaiv, woman living with HIV, raising a daughter**

4.2 Challenges and limitations, and why it matters

Reaching vulnerable subgroups: women from rural areas remained less engaged – digital tools alone, without additional strategies, do not reach them.

Formulating sensitive topics: some questions had to be revised several times to avoid re-traumatisation or refusal to participate. Variations in the coordinators' communication skills affected both the quality of data collection and the effectiveness of advocacy – further investment in skills development is required.

Increasing complexity: the addition of modules and the expansion of the geographical scope increased the coordination workload. Delays in developing the chatbot affected related activities.

Institutional constraints: the irregularity of Coordination Council meetings in the regions slowed down the conversion of data into decisions. Obtaining approval for the placement of QR materials in healthcare facilities took longer than anticipated.

4.3 Vision for the next 2–3 years

Two areas of development:

- integration of AI functions for automatic analysis and visualisation at regional level;
- and the creation of an urgent notification function – the automatic transmission of information about critical incidents to other organisations to enable a rapid response.

4.4 Recommendations for replication

- Trauma-informed survey design is not an option, but a prerequisite for high-quality data when working with key communities.
- Digital tools must be combined with community capacity-building: without analytical and advocacy skills, data does not translate into impact.
- Hybrid engagement models (online + offline) are more effective than purely digital ones.
- The development phase of digital solutions is usually more complex and time-consuming than expected – allow for extra time and resources
- Critically important: developing the communication skills of local teams, testing on small groups before scaling up, and establishing early engagement with authorities.

Authors and acknowledgements

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This publication documents the experience of the first cycle of implementing digital CLM tools and integrating community-generated data into the national information infrastructure. The content of the document is the responsibility of the authors and does not necessarily reflect the official position of EJAF, the Public Health Center of the Ministry of Health of Ukraine, or other partner organisations involved in the project.

2026

DOCUMENTATION OF BEST PRACTICES
of community-led monitoring (CLM) in Ukraine

THE EXPERIENCE OF ORGANISATIONS OPERATING
TO PROTECT THE RIGHTS AND INTERESTS
OF PEOPLE WHO USE PSYCHOACTIVE SUBSTANCES (CO CF PUD.UA)
AND WOMEN LIVING WITH HIV (CO “Positive Women”)

ELTON JOHN
AIDS FOUNDATION

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