THE POWER OF COMMUNITIES
IN OVERCOMING THE HIV EPIDEMIC

USAID-funded Project
Community Action For HIV Control

One of the main focuses of the USAID-funded Community Action for HIV Control project is to build an enabling environment for expanding access to HIV services for key and priority populations.

This thematic issue of the digest focuses on the communities and initiatives supporting our project’s efforts to advance the end of HIV in Ukraine. We share highlights of our engagement in monitoring HIV services in medical facilities and in NGOs, collaboration with the National Key Populations Platform, regional TB/HIV coordination councils, and improvement of the HIV regulatory framework.

I am always in touch with representatives from the communities served by at AIDS Centers, and it is evident that perceptions have changed. Doctors are recognizing the importance of treating key populations, leading to a more respectful and considerate approach. This is very valuable amidst the current crisis within the medical system.

Project monitor, Kharkiv region
MONITORING HIV SERVICES

After Russia’s full-scale invasion of Ukraine, concerns arose around the availability of medical services, particularly HIV services. In response, community representatives, guided by project specialists, began documenting the availability of services in their regions.

In January 2022, we started preparing for focus groups with representatives of key groups. However, on February 24, with the start of the full-scale invasion, we adapted our monitoring tools to mitigate risks. I remember how difficult it was to interview people who had just evacuated the war zone the day before.

After the initial shock subsided, the community gradually resumed its activities with people returning to community centers. This presented an opportunity to involve new monitors and informants in the survey.

Project monitor, Poltava region

Having connections with representatives of key populations, I tried to interview those with whom I had less interaction with to gain new and fresh insights. I had the opportunity to distribute humanitarian aid to key communities — and this helped me meet new informants, particularly internally displaced persons (IDPs).

Project monitor, Ivano-Frankivsk region

The National Key Populations Platform, an association of activists from key populations, helped to form the first cohort of project monitors which formed the basis of today’s team who work in 17 regions of Ukraine.

For the past two years, community representatives have been working on the ground as part of this project. During this time, they have made significant progress in monitoring efforts. They expanded their role beyond simply recording the availability of HIV services, to tracking and analyzing the accessibility and quality of service provision using various approaches and tools.
Over the past 10 years, the attitude towards patients has changed a lot in the context of HIV. Doctors are no longer shying away, horrified. In 2012, it seemed to me that if I told them about my disease, everyone would point fingers at me, even doctors.

*Project monitor, Dnipropetrovsk region*

Informants often come to me because they face service barriers services and are seeking assistance. This shows the value of community-based monitoring, as it not only identifies barriers but enables us to assist in overcoming them.

*Project monitor, Kharkiv region*

I am a representative of key populations and receive services that I monitor. For me, it is very important that a person can, firstly, receive services, and secondly, receive quality services — regardless of their behavioral characteristics, appearance, etc.

*Project monitor, Dnipropetrovsk region*

The most valuable result of the work is witnessing its positive outcomes. Monitors work hard to collect data on the availability and quality of HIV services, systematize it, and present it at meetings with the Public Health Center. Through successful collaboration with Center specialists, they facilitate productive discussions and enact operational improvements.

SECRET CLIENT

In August 2023, a pilot «secret client» project was launched, in which monitors visited medical facilities and analyzed the quality of service provision. During August-October 2023, monitors visited 24 medical facilities and identified the following problems:

- impossibility of planning and pre-registration for testing,
- lack of pre-test information and post-test counseling,
- violation of confidentiality,
- demotivating customers to take quick tests,
- offers to pay for the service or consumables,
- inability to receive HIV testing services without a family doctor’s referral (the Public Health Center promptly solved this problem).

The mystery client is the most effective tool currently available for researching the quality of services for the key populations. Together, we manage to identify «weaknesses» in the provision of services and, if necessary, influence prompt and, in some cases, systemic improvement of the situation. The secret to success is simple: intersectoral dialog and a common desire to make services more accessible and of higher quality.

*Project monitor, Kyiv region*
Now monitors are researching and analyzing the quality of service provision in health care facilities, and soon they will start testing services in NGOs a secret client will visit NGOs to get tested for HIV.

The monitoring results are constantly updated in the project’s dashboard: https://bit.ly/monitoringHIVservices

What I like about this project is that it’s not just research, but real-time decision-making to remedy the situation. It is much more effective when everything is structured and there is a clear mechanism of work: we transfer information and get solutions on how to improve the situation. It exceeded my expectations.

Join the community of monitors! The project holds regular meetings with monitors, creates a platform for exchanging ideas and experiences, and helps improve monitoring tools.

Watch the video: https://youtu.be/IPwOcRB33DA

Fill out the form: https://bit.ly/CAHC_HIV_monitoring_form

Thanks to such successful examples, the implementation of the mystery client tool was recognized at the POART meeting as one of the most significant achievements!
Despite the challenges of the war, regional TB/HIV coordinating councils continue to work in the regions, and now, more than ever, it is important that communities successfully defend their rights. The project initiated a series of workshops where community representatives, in the coordinating councils, share their experience of successful advocacy campaigns, work with the secretariat of the National Coordination Council on TB/HIV to develop algorithms for cooperation with officials, and learn how to initiate and support the implementation of community initiatives.

_Iryna Hryshayeva, Policy Advisor_

Since February 2023, the project has been training community representatives who are members of regional coordination councils, equipping them with the skills and procedures for effective participation in meetings, documenting completion and advocating for community interests.

As of March 1, 2024, the training was completed by:

- 101 participants
- 7 heads of health care departments
- 26 secretaries of coordinating councils
- 68 of them are community representatives

These helped identify more than 20 issues relevant to community representatives which have been shared with the coordination councils for consideration.

The workshops provided an opportunity to raise painful and uncomfortable issues at coordinating council meetings. We were able to reach equitable communication with council heads and secretaries. Leveraging my experience in establishing friendly communication in my region, I helped facilitate connections with other regions.

It is very valuable that at the seminars we can hear the experience of other regions. After the start of the full-scale war, the same processes in different regions began to differ. That’s why it’s important for us to learn how things are going on in other regions to know how we can apply this experience in our own

_Maryna Pohorila-Hridina, Director of the Poltava branch of Legalife-Ukraine_
we assist in to enable

- identifying community requests and formalizing them for meetings
- formulating theses and collecting pertinent information
- writing proposals for coordinating council meeting decisions
- documenting meetings (complaints, appeals, minutes, etc.)
- planning follow-up steps to monitor decision implementation

- development of regional targeted HIV prevention and treatment programs
- coordination of programs and projects at the regional level
- efficient use of resources
- involvement of the deputy corps in protecting the rights and advocacy of key populations’ initiatives
- expansion of the HIV testing sites network
- opening of new OST sites
- provision of adaptive formula to children of HIV-positive mothers
- allocation of local budget funds for HIV prevention programs in the region
- activities to raise awareness about HIV and the importance of regular testing

Being meticulous is a must for a public figure. When you are a member of the coordinating council, knowing the regulations and rules means being able to influence decisions, shape the agenda, attract support and overcome government inertia.

**Member of the coordinating council**

At the workshops, attention is paid to building horizontal connections through practical exercises and informal communication:

1. with the chairpersons and secretaries of the coordinating councils in addition to training community representatives on the specifics of the procedures and relevant documents;
2. between members of coordinating councils in the same or different regions.

Our joint efforts are yielding results, ranging from the development of regional HIV strategies to enhancing the quality of service delivery at individual facilities.
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