

Using Data from Electronic HIV Case Management Systems to Improve HIV Services in Central Asia





BACKGROUND

HIV incidence continues to rise in Central Asia and Eastern Europe. Between 2010 and 2015, there was an estimated 57 percent increase in new infections each year.¹ By 2015, there were 1.5 million people living with HIV in the region, only 20 percent of whom were accessing antiretroviral therapy (ART).² Programmatic responses are urgently needed to increase ART coverage, as well as levels of patient adherence to treatment and retention in care.

Health systems require robust strategic information to support an effective, targeted response to the HIV epidemic. With the relevant, accurate, and comprehensive information readily available, HIV care and treatment programs can be designed to best meet patient needs and program goals, and to effectively curb transmission. Electronic health information systems can provide such high-quality information and can reduce the reporting burden associated with paper-based systems, thus allowing clinicians to spend more time on patient care.

Until 2009, clinics providing HIV care and treatment in Kazakhstan, Kyrgyzstan, and Tajikistan relied on paper-based records to collect patient data. Data were collected by each provincial and local AIDS Center and sent to the national Republican AIDS Center for aggregation. Data on patient records were often entered inaccurately and unsystematically, and reporting at the national level lacked standard definitions and calculation methods for indicators. At the service delivery level, paper-based reporting was cumbersome and time-consuming, making it difficult for clinicians to follow up on patient management, including assessing ART adherence, conducting lab monitoring with CD4 counts, and reviewing treatment results. At the national level, the paper-based system made it difficult to conduct comprehensive data analyses and identify and interpret trends.





¹Prevention Gap Report. UNAIDS; 2016.

² Fact Sheet 2015. UNAIDS; 2015.

PROJECT SUMMARY

Since 2010, with funding from PEPFAR through the Centers for Disease Control and Prevention (CDC), ICAP has supported the ministries of health of Kazakhstan, Kyrgyzstan, and Tajikistan to develop and support the rollout of a robust, state-of-the-art, confidential electronic HIV case management system (EHCMS). The system was designed to allow health workers to record and monitor individual HIV cases and to provide health managers with the data needed to assess aggregated HIV care and treatment indicators and compare them by region, age, sex, etc.

Building on the work begun with support from the World Bank-funded Central Asia AIDS Control Project in 2009, ICAP began managing the EHCMS rollout in 2011. With the ultimate goal of improving the quality of care and treatment programs available to people living with HIV in Kazakhstan, Kyrgyzstan, and Tajikistan, ICAP focused on creating a system capable of providing real-time, accurate, and easily accessible patient data to clinicians, as well as a system that would facilitate data-driven decision-making by health managers, policymakers, and other key stakeholders.

The EHCMS was rolled out in stages over the course of four years: first it was implemented at several pilot sites in Kazakhstan, and then it was adapted for use in Kyrgyzstan and Tajikistan and piloted at two sites in each country. Subsequently, the system was rolled out gradually across Kazakhstan, Kyrgyzstan, and Tajikistan in facilities run by the Republican AIDS Centers, provincial AIDS Centers, local AIDS Centers, and family medicine centers.

The governments of Kazakhstan and Kyrgyzstan called for a nationwide rollout of the EHCMS in 2012 and have since adopted the system as the primary means of national HIV surveillance. In Tajikistan, the EHCMS has been rolled out nationwide, but runs in parallel with the existing paper-based system.

The EHCMS has three key functionalities:

Individual Electronic Care Records

Each patient that has visited an HIV care and treatment site that uses EHCMS has a patient record that includes socio-demographic data (e.g., name, age, education level), epidemiological data (e.g., HIV testing year and results, place of infection, mode of transmission, sexual and drug use behaviors), laboratory data (e.g., HIV, CD4, and viral load test results), and clinical data (e.g., vaccination record, TB history, physical exam results, ART-related data). Data in this module is populated by clinicians from standardized paper patient case records that are entered into facility-level databases.



"This system helps ensure better management of HIV patients, including planning and management of their visits and routine screenings, such as TB screening and treatment monitoring. Its features allow prompt and easy generation of different HIV care and treatment reports that have information on various indicators, which allows us to adapt the work of clinical departments in order to improve the quality of HIV services."

Dr. Sairankul Kasymbekova Republican AIDS Center, Kazakhstar

Automated Report Generation

Once data for each patient has been entered into the system, it can be retrieved, aggregated, and sent for analysis to the oblast- and national-level AIDS Centers to meet reporting requirements, including those related to HIV incidence, mortality, and survival rates.

ARV Supply Management

This module was developed in 2014 to enable HIV care and treatment centers to plan, manage, and forecast their need for ARV drugs, and to track expiration dates in order to reduce drug stock-outs.

CORE PROJECT APPROACHES

ICAP used the following approaches to support the effective rollout of the EHCMS in Kazakhstan, Kyrgyzstan, and Tajikistan:

Aligning EHCMS With Existing National Requirements

ICAP helped ensure buy-in from key stakeholders for the EHCMS by aligning the data capture tools with existing national reporting requirements and national HIV program indicators. This assured partners that the system would generate the information needed without any duplication of efforts.

Ensuring Completeness of Data

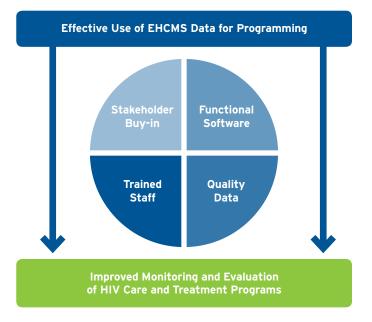
To make the system as comprehensive and useful as possible, ICAP supported the AIDS Centers in each country to conduct retrospective data entry. A complete set of records on all individuals who have tested HIV-positive now allows the generation of comprehensive reports, including the ability to summarize historical data against which current trends can be measured.

Providing Targeted Training and Mentorship

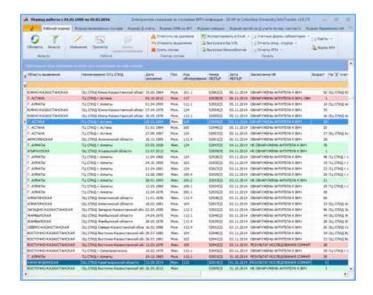
ICAP used a variety of training and support approaches to improve computer literacy among providers, address the learning needs of different users, and troubleshoot technical challenges. Tailoring the training methods used allowed ICAP to have the greatest impact while also meeting specific user needs.

- Training seminars: Large-scale, recurring trainings were provided to health professionals on EHCMS features and functions. Clinical management teams and selected clinicians participated in the initial trainings, while follow-up trainings included nearly all clinicians using the EHCMS. Separate sessions were provided to clinicians and epidemiologists, with content tailored to their specific roles related to data entry, generating patient lists (e.g., patients needing a specific test), and using reports to identify trends and areas needing improvement.
- On-site mentorship: ICAP health management information specialists and strategic information specialists conducted regular site support visits to train and assist local AIDS Center staff to solve problems related to data entry and the generation of reports. These mentorship visits were used as an opportunity to identify issues and bottlenecks in the use of EHCMS and to work with clinicians and department heads to resolve these challenges. Information gained through these visits also helped identify additional data needs, which enabled further improvements to the EHCMS system (for example, based on user feedback, a data field was added to the EHCMS to capture observations on possible TB symptoms and coinfection).

Figure 1. How the EHCMS Improves HIV Program Monitoring and Evaluation



- Development of user manuals: To support formal and ad-hoc trainings on the EHCMS, ICAP developed two comprehensive handbooks on data collection and quality control (one for epidemiologists and one for clinicians).
 Copies of these manuals were distributed to all facilities using the EHCMS.
- **Remote support:** When technical issues arose, ICAP staff was available via Skype to provide troubleshooting support to EHCMS users.
- Increasing data quality: ICAP worked closely with the ministries of health and Republican AIDS Centers to conduct data quality assurance aimed at improving data completeness and accuracy. Electronic data was cross-checked with other data sources, such as paper-based patient records and clinic registers, and discrepancies were reported and recommendations given on how to remedy the discrepancies. In addition, ICAP developed standard operating procedures to guide the data quality assurance process and ensure that all patient data be kept secure and confidential. ICAP conducted data quality assurance visits jointly with the Republican AIDS Center, building their capacity to ultimately conduct this function independently.



Top left: Users can access information on all registered HIV cases and filter information by data field.

Bottom: Users can generate graphs using epidemiological data, such as the total registered number of HIV cases over time (**left**) and the total registered number of HIV cases by transmission mode (**right**).





WHAT WAS ACHIEVED

- The EHCMS has been rolled out in **77 centers** in the region (24 in Kazakhstan, 23 in Kyrgyzstan, and 30 in Tajikistan).
- The EHCMS now houses data on more than **46,000 patients** across the three countries, and data quality assurance visits are carried out at all implementation sites.
- The EHCMS has been adopted as the primary means of national HIV surveillance in Kazakhstan, Kyrgyzstan, and Tajikistan.
- Training on EHCMS was delivered through **26 training and mentoring sessions** that included more than **120 staff** at **77 facilities** in the three countries.
- The ARV planning module has been incorporated in the EHCMS in **23 centers** in Kazakhstan, including local AIDS centers and branches.
- The "Salamatty Kazakhstan" national health conference, which was held in November 2015, was the first to use EHCMS data to demonstrate and help explain major trends in the country's HIV epidemic.

LESSON LEARNED

- → Government buy-in and support was critical to success. The support of national governments was crucial to the success of rolling out the EHCMS. In Kazakhstan, Kyrgyzstan, and Tajikistan, the ministries of health issued formal announcements calling for the implementation of the EHCMS nationwide and recognizing the new system as the primary source of HIV surveillance. This support ensured high levels of commitment from sub-national users, including strong health worker commitment to data quality and completeness. Time and investment spent training and working alongside government counterparts to conduct data quality assurance helped strengthen local leadership and the coordination role of the Republican AIDS Center, and ultimately enhanced confidence in the HIV care and treatment data being reported.
- → Phased implementation led to smooth implementation. By rolling out the EHCMS in phases, problems could be addressed early on and before subsequent rollout to other sites. This approach also allowed for the gradual introduction of upgrades, including additional modules over time to avoid overwhelming AIDS Center staff as they learned to use the new system. Most recently, this phased implementation approach was applied to the ARV planning module, with the monitoring functions rolled out first and the forecasting tools rolled out in a subsequent phase.
- Continuous feedback facilitated the development of an effective, easy-to-use system. ICAP worked to ensure that all stakeholders-from project managers to system users, policymakers, and government partners-had the opportunity to contribute to the EHCMS development and implementation process. Open, regular communication allowed for barriers to use and system issues to be identified and addressed early on, improving the implementation and ultimately strengthening the EHCMS. Examples of improvements made as a result of user feedback include the simplification of filtering parameters, the creation of additional reporting forms, and the creation of TB/ HIV co-infection data fields.
- → Tailored and targeted support to end users led to comprehensive adoption. ICAP used a variety of training and mentorship methodologies for end users of the EHCMS and continually explored new ways to reinforce learning and increase the system's user-friendliness. From formal trainings to on-the-job mentorship, ad hoc on-site sessions, and remote support, the variety and tailored ways that ICAP provided support to EHCMS users helped drive the successful adoption of and commitment to using the system across all levels of the national health system.

"Now we can track the clinical and laboratory changes of patients who came to the cities from other areas. We can also obtain statistical data for any interval of time in the Republic, disaggregated by region. The process of data exchange between AIDS Centers has become quicker. In cases where patients were not identified in a specific region, it is now easier to find them in the system. Previously, it was necessary to send requests about the patient to other AIDS Centers, which made the process slow. Now, with the EHCMS, it takes just a phone call or communication via Skype and the whole history of the patient can be traced. In addition, information about patients, such as HIV status and ARV treatment, can be tracked through the EHCMS even if the patient did not show up for appointments. Introduction of the ARV Supply Management Tool also simplified our work in monitoring the use of ARVs before their expiration dates."

Dr. Abraimov S. Astana City AIDS Center, Kazakhstan



"A distinctive feature is the ability to not only store information, but also to analyze it. This program works in real time."

> Marat Tukeyev CEO of Republican AIDS Center



THE WAY FORWARD

The EHCMS serves as an example of an effective approach to implementing an electronic health information system. ICAP plans to build on the success of the EHCMS initiative by continuing its work with local partners in Kazakhstan, Kyrgyzstan, and Tajikistan to:

- Expand the scope and reach of the EHCMS: ICAP is continuing to work with partners to roll out the EHCMS to new sites providing HIV care and treatment services, including branch facilities and family medical centers in Kazakhstan, Kyrgyzstan, and Tajikistan.
- Adapt and improve the EHCMS: The EHCMS is being continuously adapted and improved based on lessons learned from implementation. For example, the new ARV module was originally designed to fulfill a forecasting function, but piloting revealed that its most useful feature was in fact the supply management function (i.e., assisting pharmacists to manage ARV supply and reduce stock-outs at each site). With this in mind, the module continues to be rolled out across the three countries. It is anticipated that the EHCMS will eventually be moved to an online platform, enabling increased flexibility and user-friendliness. In addition, reporting functionality will be expanded, including increasing users' ability to generate graphical content and data reports.
- Strengthen the capacity of the national health system: Through ongoing training and mentorship, the Republican AIDS Centers are gradually assuming greater responsibility for the management and oversight of the EHCMS. For example, ICAP has successfully transitioned all routine data quality assurance activities to the Republican AIDS Center in Kazakhstan, while continuing to provide ad hoc support. Republican AIDS Centers are now actively using data from the EHCMS to present national HIV trends to partners and funders at conferences, and to identify specific needs. ICAP will continue to support the Republican AIDS Centers to use data for decision-making and improving the quality of HIV programs.

ICAP is also working with partners to apply the lessons learned from the rollout of the EHCMS to similar initiatives in the region; for example, to the development and implementation of a stand-alone electronic medication-assisted treatment registry in Kazakhstan, Kyrgyzstan, and Tajikistan.



ICAP was founded in 2003 at Columbia University's Mailman School of Public Health. Now a global leader in HIV and health systems strengthening, ICAP provides technical assistance and implementation support to governments and non-governmental organizations in more than 21 countries. ICAP has supported work at more than 5,200 health facilities around the world. More than 2.2 million people have received HIV care through ICAP-supported programs and over 1.3 million have begun antiretroviral therapy.

Online at icap.columbia.edu

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