

SHORT COMMUNICATION

The medical information system “HIV-infection in Ukraine”: development and implementation

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ABSTRACT

Easy access to medical data on people living with HIV can improve the level of their medical care and allow for better planning in the procurement of antiretroviral medicine. Taking into account current situation regarding HIV in the country, decisive steps in the development of health-care related information systems are needed. However, the development and implementation of a national medical information system is a complex and lengthy process that not only requires the involvement of technical

specialists but medical personnel, who understand the need for a functional system and can describe in detail the processes that need to be automated.

This article evaluates the experience gained from the development and implementation of the medical information system “HIV-infection in Ukraine” in healthcare facilities at local, regional, and national levels including its preparatory measures, design and preliminary tests, pilot introduction and trial operation stages, and the difficulties encountered at each stage and ways they were minimized.

Keywords: HIV/AIDS, HIV IN UKRAINE, MEDICAL INFORMATION SYSTEM, PEOPLE LIVING WITH HIV, ANTIRETROVIRAL THERAPY

INTRODUCTION

The fight against HIV/AIDS remains a priority in Ukraine, particularly in reducing infection and mortality rates, as well as providing adequate care for people living with HIV (PLHIV). As of 1 January 2019, there were an estimated 242 000 PLHIV in Ukraine, with 40.3% receiving antiretroviral therapy (ART) in total, and 35.9% having been receiving ART for more than six months and achieved an undetectable viral load. At the beginning of 2018, there were 141 371 PLHIV registered at medical institutions, and an increase was seen in comparison with 2017 in the number of PLHIV (18 194 people) registered for the first time. The rate of PLHIV aware of their HIV status, following a medical diagnosis, has reached 79%, but almost half of newly diagnosed patients had only presented at medical institutions when they are already at stages III–IV (1).

One of the key problems in combating HIV/AIDS in Ukraine is that management decisions are not sufficiently comprehensive, timely, or substantiated. One reason behind this was the lack of

a unified approach in the mechanisms used to collect and process information at State medical institutions between the national (Public Health Centre of the Ukrainian Ministry of Health (PHC of the MOH of Ukraine)), regional (regional and city AIDS Prevention and Control centres), and local (private consulting offices and antiretroviral medicine distribution points in local clinics and hospitals) levels.

The development and introduction of the medical information system “HIV-infection in Ukraine” (MIS HIV) aimed to solve this problem with the creation of a unified repository for routine HIV/AIDS epidemiological surveillance data and medical results of PLHIV, to help to optimize monitoring and evaluation, drug procurement planning and the registration and control of medical drugs and devices. As of the end of 2018, MIS HIV was routinely used at 748 medical institutions, with the number of users reaching 2 863. The system stores information on more than 150 000 patients diagnosed with HIV, and the results of 370 000 laboratory tests and 350 000 consultations with infectious disease physicians.

THE NEED BEHIND THE DEVELOPMENT OF MIS HIV

It is worth mentioning that Ukraine had previously introduced a system to record and keep track of PLHIV, called EpidAIDS. However, this system failed to meet the requirements of HIV/AIDS specialists for a number of reasons. First, it only allowed for local data management without any centralized control. Secondly, for data to be analysed at the national level it had to be manually downloaded and transmitted. EpidAIDS was viewed as a registry; recording individual HIV cases, but without the availability of a patient's electronic medical record (EMR), thus, no other medical data, such as other diagnoses, results of laboratory tests and physical examinations, were accessible from the system. Moreover, the programme had limited analytic capabilities and failed to take into account the management system behind antiretroviral medicine supply and its various sources of funding. Thus, the need arose to create a system that would optimize the health-related monitoring and control of PLHIV.

Prior to the development of MIS HIV, medical institutions faced a number of problems with information management, such as the lack of a unified approach to the design of standard documents; a low level of efficiency in information exchanges between medical institutions; the multiple entry and duplication of medical information; the inability to get an overview of the HIV situation in Ukraine, or on the number of drugs and medical devices; labour-intensive reporting; and the need to generate data manually for it to be entered into international information systems. Developing the new system allowed for the elimination of these problems as well as improving the quality of care for PLHIV. The development of MIS HIV involved achieving the following goals:

- enhancing the reliability of medical information about patients by minimizing possible errors;
- ensuring the collection and storage of information concerning the health status of PLHIV and the medical services provided to them;
- optimizing budget management, and monitoring the logistics of providing antiretroviral medicine;
- efficiently providing doctors with relevant data on the health status of PLHIV;
- providing supporting information for epidemiological surveillance and clinical monitoring systems.

DEVELOPMENT OF THE TERMS OF REFERENCE AND THE DESIGN OF MIS HIV

The work to create MIS HIV started with a discussion with national and international HIV/AIDS organizations about the need for a medical information system in Ukraine. In early 2015, an invitation for bids was help to develop the terms of reference for MIS HIV as part of a programme implemented for the tenth round of a grant from the Global Fund to Fight AIDS, Tuberculosis, and Malaria entitled 'Development of a long-term system to provide comprehensive services for the prevention of HIV/AIDS, treatment, care, and support among most-at-risk groups and PLHIV in Ukraine'.

A team of selected developers based the system on a number of guidelines, which highlighted the need for: the ability to adapt functional modules, to other medical conditions for example; a unique identifier for each patient in the system; the one-time input and multiple use of primary information at medical institutions; legal responsibility for tracking an HIV-infected patient requiring authentication via a digital signature; openness to integration with external and related information systems; compliance with the requirements of building an integrated information security system; support of the main formats used for exchanging information with other information systems; the depersonalization of data in the system to allow for secondary use; and the need for minimal changes in the organizational structure.

In order to optimize the development of MIS HIV during the design stage, meetings were held among various working groups, which included primary health-care experts from the MOH of Ukraine, members of the charitable organization All-Ukrainian Network of People Living with HIV, and regional health-care facilities. In addition, joint work by the potential users of MIS HIV at national and regional levels made it possible to develop a convenient interface for the system and to eliminate many potential issues already at this stage.

The decision was made to place the MIS HIV software on servers using cloud technologies. This makes it possible to rapidly change the server configuration, which is essential given the potential growth dynamics. This approach is also cost-effective compared to buying servers.

During the development of MIS HIV, special attention was paid to protecting the data of PLHIV in accordance with Ukrainian law. A comprehensive system that protects the information on

MIS HIV was developed to prevent the unauthorized access, deletion, or distortion of data and the loss of access to such data. MIS HIV was the first medical system in Ukraine to have been tested by, and to have received an expert testimony from, the Ukrainian State Service of Special Communications and Information Protection, which guarantees the safeguarding of data and its storage in an encrypted form on secure servers.

IMPLEMENTATION AND PILOTING OF THE SYSTEM

The following pilot regions were selected during the initial stage of the introduction of the MIS HIV: Kyiv city, and the Poltava and Vinnytsia Regions.

The main difficulties encountered during this stage were providing computers to medical institutions and the low level of computer literacy among medical personnel. All medical institutions in the pilot regions were provided with Internet access, computer technical maintenance and of course, computers.

In fact, since the pilot introduction of MIS HIV, more than 700 computers have been purchased for PEPFAR regions (the U.S. President's Emergency Plan For AIDS Relief), which include 12 regions of Ukraine, in which 70% of the HIV epidemic is concentrated, and another 400 computers were purchased for all other regions.

With the medical personnel not having the proper skills to work with the information systems, the pilot process was slower than anticipated. Progress was further slowed by the underestimation of the capabilities of an automated system; medical personnel were simply not ready to switch over to keeping EMRs, as they did not understand its benefits. A further problem was that highly-educated specialists had to study a new field entirely from scratch and spend a large amount of time doing so. To this end, specialized training sessions were held to help users, and a test platform was created for interactive training on the use of MIS HIV. Given the growing number of requests from health professionals to work with the information system, user support was introduced on a remote basis, which helped create a more loyal attitude to the programme that was being introduced. Feedback was collected from users in the pilot regions (using a purposely developed electronic questionnaire) in order to improve and modify MIS HIV.

REFINEMENT STAGE

Another eight strategically important regions with high HIV rates joined the programme from mid-2016 (2), and an additional 13 regions began introducing MIS HIV in 2018. Extending the system to all regions of Ukraine made it possible to expand its capabilities, including the ability to track duplicates within the system and the analysis of antiretroviral medicine distribution.

Additional challenges have been identified with the increase in number of medical institutions and users involved in the system. The large-scale transition from paper to electronic registration of PLHIV meant that retrospective data from medical records and other tools had to be input, which required additional time by health professionals and developers. However, doing this made it possible to encompass both new and previously detected cases of HIV into the system. To date, HIV cases detected prior to the implementation of the pilot system account for 75% of data entered into MIS HIV.

Despite the fact that MIS HIV is now nationwide, medical documents are currently kept in two forms – paper and electronic. As stated above, duplicating information requires time and effort from health professionals, which can affect the quality of the data recorded (for example, not all information from a paper medical record is entered into MIS HIV). The ability to print out a complete patient record was introduced for the convenience of working with the system and to reduce the time spent on such work.

As the number of regions and medical institutions using MIS HIV expanded, so did the number of users, referrals, and consultations. At the end of 2018, the PHC of the MOH of Ukraine created a separate division to provide support to MIS HIV users; employing five specialists to provide remote support to existing users and to train new users by conducting both training sessions and by using remote training tools. Furthermore, appropriate guidance materials were prepared to provide a sufficient understanding of the basics of MIS HIV. Work was also initiated to create webinars on the main aspects of the information system aimed at infectious disease doctors, tuberculosis doctors, drug warehouse workers, and laboratory specialists. This made it possible to increase the level of confidence in using MIS HIV among the users of regional health-care facilities and improve the quality of the medical data entered into the system.

STRUCTURE OF MIS HIV

As per the terms of reference, seven HIV MIS modules were developed in an effort to meet all the needs of health-care professionals in the management of HIV information, (Table 1). The access rights of health-care personnel to each particular module depend upon their competences and professional duties. This was achieved due to improvements in the information system and its phased introduction into the daily activities of medical institutions (2).

A role assignment system was developed within MIS HIV in order to optimize its use by medical personnel. Thus, the interface and the programme modules available for viewing or editing were dependant on this assigned role, which made the use of MIS HIV more convenient and simplified the process of training users to the system.

When creating the system, the development team spent a lot of time at medical institutions in order to understand and be able to modify the system at each stage of the patient's pathway (for example, the duration of each stage, the algorithm for entering data about a patient by a health professional, etc.) (Fig.1).

REPORTING TO TESSY¹ AND PEPFAR²

The data of MIS HIV are also used to generate national (3, 4) and international reporting on the monitoring of the HIV/AIDS epidemic as part of the Global AIDS Monitoring and reporting to PEPFAR. In 2017, Ukraine managed to collect data on new HIV cases in the format of the European Surveillance System (TESSy) for the first time as a result of MIS HIV implementation.

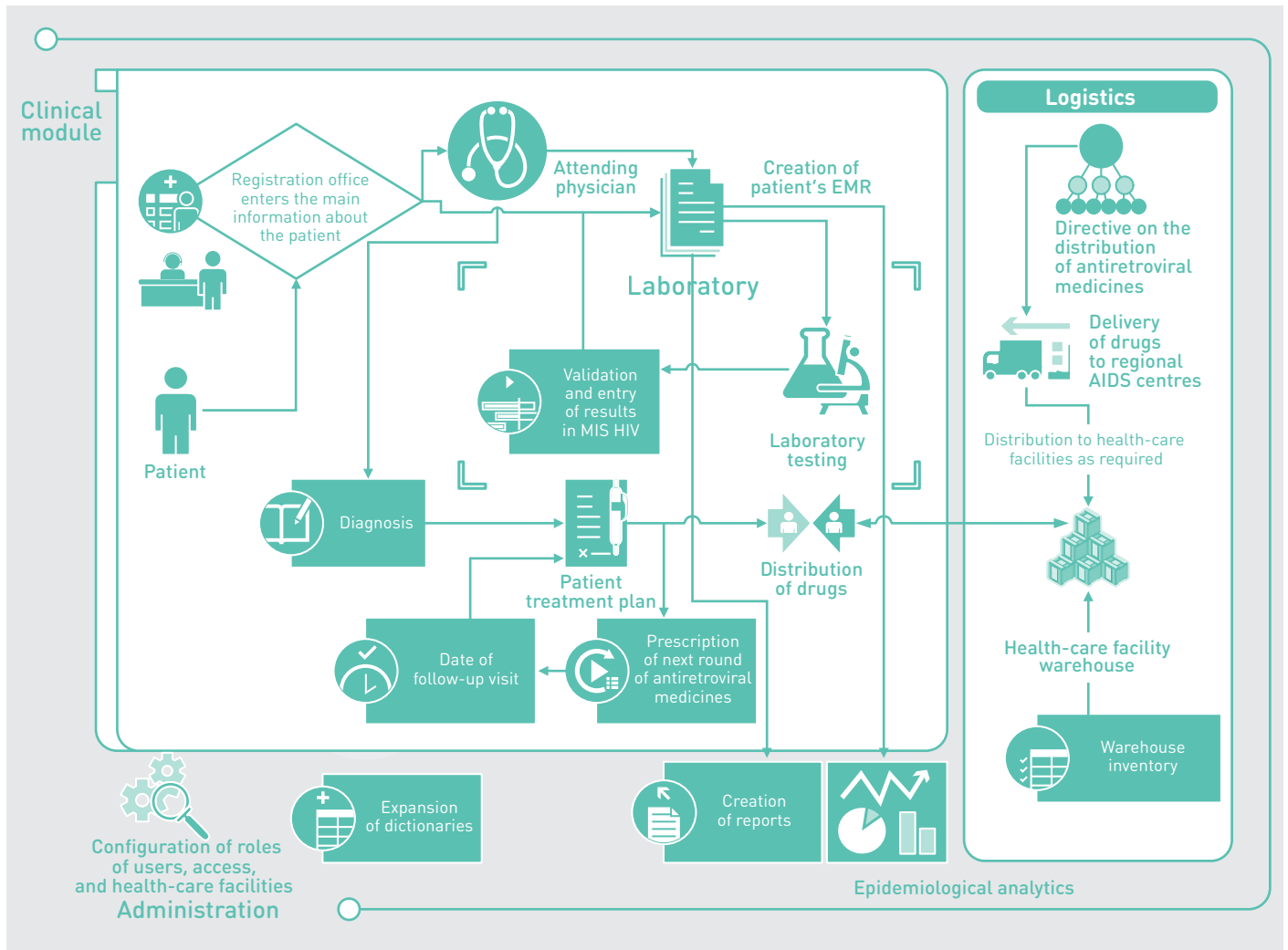
TABLE 1. PURPOSE AND CAPABILITIES OF MIS HIV MODULES

No.	Module	Purpose and capabilities
1	Information about patients with HIV	Introduction to the information in the medical records of PLHIV registered with medical institutions (results of primary and follow-up examinations, diagnosis, prescribed ART regimen, confirmation that medicines were received, etc.)
2	Epidemiology	Search electronic medical records using specified parameters (for example, ART regimen); view patients' medical indicators in summary form; generate analytical reports using standardized state forms. The module allows epidemiological studies to be conducted and the subsequent development of methods and procedures for effectively combatting HIV.
3	Clinical monitoring	Search electronic medical records, monitoring the registration and management of PLHIV patients (examination, diagnosis, prescribed treatment plan and ART regimen, and treatment monitoring). The module simplifies the treatment process by storing dosage regimen data, and has the capability to remind the patient about it through messaging or notifications via a mobile app.
4	Laboratory	Recording of referrals for laboratory tests, the registration of samples and the results of laboratory analysis, as well as the subsequent generation of reports taking into account the laboratory logbook used.
5	Logistics	Storage of information about directives from the MOH concerning the distribution of drugs and medical devices. The module can record warehouse acceptance of inventory items, track movement between warehouses, conduct inventories, generate write-off certificates, and monitor the balance of drugs and devices.
6	Reports	Generating statistical reports for internal use at medical institutions and for submission to the State Statistics Service. The module simplifies the generation and collection of national reports and minimizes the possibility of errors in aggregating data by using standards described in directives from the MOH of Ukraine.
7	Administration	Granting users their appropriate rights within the system, delimiting access rights to information, and configuring user authentication. The module allows an administrator to configure user rights and mode access according to professional duties.

¹ The European Surveillance System.

² The U.S. President's Emergency Plan for AIDs Relief.

FIG. 1 A PATIENT'S PATHWAY AND ITS LINK TO HIV MIS MODULES



ACHIEVEMENTS OF MIS HIV AND FUTURE PROSPECTS

The introduction of MIS HIV has had a number of positive outcomes in the field of HIV/AIDS at the various administrative levels. At the local level, for example, the system guarantees a reduction in the number of errors in completing medical documentation and the efficiency of information exchange. At the regional level, it allows for the maintaining of records and the auditing of drugs and medical devices at health-care facilities. The most significant benefits however, have been at the national level, since the system establishes a unified approach to coding PLHIV, avoiding repeat registration, and allows for the monitoring of the need for drugs and medical devices, and

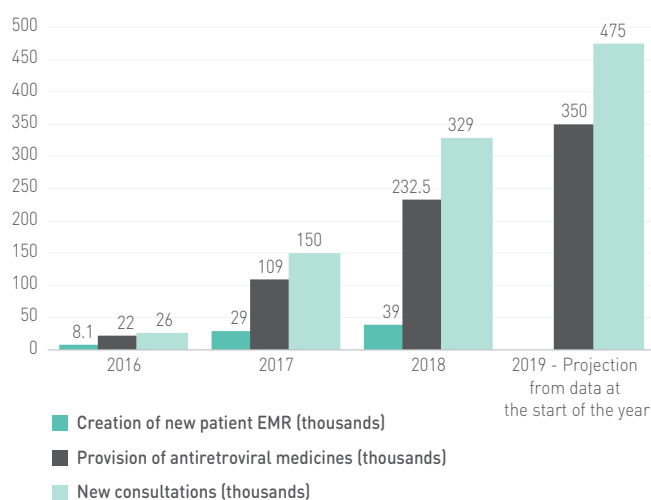
enhances the accessibility and accuracy of information on the HIV epidemic in Ukraine.

The data obtained from MIS HIV can also help to enhance the effectiveness of management decisions as they can more easily be based on factual evidence (5), and because of the availability of data, the system not only meets the demands of health professionals, but also those of specialists working in epidemiological surveillance, monitoring, and the evaluation of programmes aiming to reduce the incidence of HIV/AIDS. At present, one of the most important focus areas relating to MIS HIV is to conduct research using the acquired data, and to prepare reports on the response to HIV/AIDS.

The medical records on MIS HIV have already been used to conduct operational research in Ukraine. As an example, Figure 2 shows the dynamics of quantitative indicators from MIS HIV and the forecast for 2019:

- number of newly created patient EMRs
- number of antiretroviral medicines provided and
- number of consultations with specialists.

FIG. 2. QUANTITATIVE INDICATORS IN MIS HIV



Such data allow for the analysing of the indicators of quality of life and adherence to treatment by age, sex, region of residence, treatment regimen and other indicators. It is now becoming possible to analyse the indicators of quality of life and compliance with treatment, and to breakdown this information by age, sex, region of residence, treatment regimen, and other factors. The use of MIS HIV saves money and human resources on research since the required data can be downloaded from the system without health professionals having to manually collect information from the patients' medical records. In addition, data from the system can be used as a basis for calculating the sampling population in a number of other studies based on age and gender characteristics or region of residence.

One example of the use of data obtained from MIS HIV is a study on the national assessment of the introduction of optimized ART regimens. The study was launched by the PHC of the MOH of Ukraine in 2018 in order to build an evidence base for the effective transition of ART treatment regimens from an enhanced Lopinavir to a Dolutegravir regimen. In addition to its primary results, the study has had secondary benefits for MIS HIV. Specifically, it helped evaluate the

completeness and accuracy of the data in the system so that they can be fully utilized in future assessments, and it also analysed the capabilities of MIS HIV to be regularly used in the context of national level policy assessments.

Patients are identified in MIS HIV both by internal coding and by the coding of nongovernmental organizations that provide social and medical support for HIV-positive patients. Such organizations include the aforementioned All-Ukrainian Network of People Living with HIV (Case ++ database) and the Alliance of Public Health International Charitable Foundation (Syrex database), which are the main organizations in Ukraine that provide these services for PLHIV. This will make it possible to not only track the treatment of PLHIV, but also study their patient pathway, their compliance, and the quality of services provided.

Currently, all the conditions have been created for the effective tracking of patients using only the electronic system. During the pilot and trial operations, the case management procedure was greatly simplified due to drop-down lists; templates for standard consultations by infectious disease physicians, diagnoses and medicine prescription; and the availability of various medical reference guides. This meant that the duration of a single consultation with an infectious diseases specialist decreased from 20 to 15 minutes, provided that the information collected electronically was printed out (and not rewritten by hand) and included in the paper records.

BOX 1.

An analysis of MIS HIV users showed that the average consultation time with an infectious disease physician over the years was:

- 2016 - 21 min
- 2017 - 22 min
- 2018 - 17 min
- 2019 - 15 min

CONCLUSIONS

The introduction of MIS HIV in Ukraine is an illustrative example of how to create a unified medical information system at a national level, streamline work to aid the fight against HIV/AIDS, and improve the quality of medical care provided to PLHIV. Over the last four years MIS HIV has demonstrated its effectiveness compared to traditional information management approaches and systems that have been created in the past. Since 2014, it has become possible to develop, test, and introduce an information system in all regions of Ukraine, and

in 2019 the capabilities of MIS HIV are to be further expanded to fully support the prevention and treatment of PLHIV.

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³ All references were accessed 20 March 2019.