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Implementation of a Case Management System for PMTCT Monitoring and Evaluation in Resource-limited Settings

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BACKGROUND

Although the number of infants born to HIV+ women in WHO's European Region is still relatively low, two-thirds of these children are delivered in Ukraine.¹ With HIV prevalence approaching 1% of the adult population in the country,² the number of children born to HIV+ women in Ukraine increased from 727 reported cases in 2000 to 1,379 in 2002.³ The percentage of HIV cases registered among pregnant women has increased in some regions of the country to more than 0.4%; in the Odessa Oblast the current rate is 1%.⁴



WHO's strategy in the European Region for preventing infants from becoming infected with HIV is to assist countries to step up their response to the broader epidemic. To accomplish this, WHO recommends integrating specific prevention of mother-to-child transmission (PMTCT) interventions into existing maternal and child healthcare (MCH) and reproductive health (RH) services as a way to provide all women with HIV preventive care (testing and counseling, STIs diagnosis, etc.).

This approach can present major challenges as it involves shifting from the vertical structures through which HIV/AIDS programs have often been organized to integrating services around the needs of HIV patients.⁵ This paradigm shift from institution- to patient-centered care requires a restructuring of the healthcare delivery model, as well as the active involvement of different organizations, including non-governmental groups.

Integration of services is particularly challenging in terms of the early identification and referral of women from high-risk populations to PMTCT programs—approximately 36% of HIV+ pregnant women in Ukraine are from vulnerable groups⁶—and requires the development of strong links with outreach organizations who help people living with HIV/AIDS.

WHO's strategy also stresses the importance of closely monitoring PMTCT interventions and programs. In particular, it is important to determine why and where women are "missed" by the system and to adjust services accordingly. As such, information should be gathered at more than one point/activity in the healthcare delivery process to determine where the system may fail or gaps occur. Large maternity hospitals situated close to vulnerable populations and/or located in geographic areas where HIV prevalence is high are key places at which to measure the progress of implementing a PMTCT strategy.⁷

Currently, at most healthcare institutions in the countries of the former Soviet Union, PMTCT monitoring and evaluation is based on paper records and is fragmented and inefficient. In Ukraine, for example, the Ministry of Health (MOH) explains its PMTCT program monitoring, initiated in 1999, as follows: On an annual basis, the MOH develops a questionnaire and obtains report on their performance using this form. The reports are analyzed at a central level and information on program improvements is sent back to the oblasts.⁸ Such an approach does not represent a case-based management system and therefore does not enable healthcare providers and program managers to monitor progress on a regular basis or to react quickly to challenges as they emerge.

To effectively monitor and improve program performance, WHO recommends the establishment of a simple data collection system within public and non-public facilities to regularly gather data for key PMTCT indicators. Specific WHO recommendations for PMTCT monitoring and evaluation (M&E) are under development.

The Odessa +PMTCT+ Model

In response to increasing HIV-infection rates in their region, in 2001, Odessa Oblast Hospital (OOH) initiated a project to address vertical transmission of HIV.⁹ Odessa's Model is defined as a +PMTCT+ approach because it provides comprehensive pre- and post-pregnancy components in addition to traditional PMTCT services (see poster #ThPeB7020 for a description of the Odessa Model).

All HIV+ pregnancies and deliveries in the Odessa Oblast are referred to OOH, which is located on the outskirts of the city of Odessa, in a section known as "Palermo." This area has a high prevalence of intravenous drug users (IDUs), many of whom are infected with HIV. According to WHO's strategy, the location of OOH represents an opportunity to bring services closer to those most in need and to measure the progress of a PMTCT implementation strategy.

PMTCT CASE MANAGEMENT MONITORING

An essential element of the Odessa +PMTCT+ Model is its case-based management monitoring system. This type of system transcends institutional boundaries and provides information across a multi-institutional continuum of care, which is essential for the effective treatment of individual patients. It also provides the information necessary for healthcare workers and decision-makers seeking to establish effective quality improvement processes.

A computer-based data collection system was developed in Odessa—using an approach to PMTCT M&E recommended by WHO, UNICEF, and UNAIDS—that allows providers to gather and analyze relevant patient information.¹⁰ This database pro-

gram is available in Russian on CD-ROM with corresponding guidance on installation, data entry, and analysis. It can easily be adapted for, and widely used, in resource-limited settings, particularly in the countries of the former Soviet Union, which have similar healthcare delivery systems.

When developing the database, internationally accepted PMTCT indicators were reviewed and adapted for relevance to the Ukrainian healthcare system, epidemiological situation, etc., by the Odessa PMTCT team. Several indicators (e.g., exclusive breastfeeding) were modified to reflect established practices (e.g., replacement feeding). The database was then created in MS Access for 31 selected indicators, grouped into four main sections:

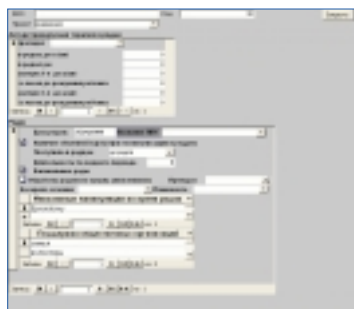
- prenatal period;
- delivery and postpartum;
- newborn information; and
- follow-up care for mother and child (see Table 1).

These sections and corresponding indicators reflect the integration of PMTCT services into the MCH system and provide the basis for case management monitoring.¹¹

MCH schedule	PMTCT interventions
Family Planning/ RH services	HIV/STI prevention counseling
Prenatal visit 1	HIV/STI counseling (pre-test) HIV testing, STI screening Anemia prevention
Prenatal visit 2	Confirmation of HIV+ status/counseling STI treatment ARV prophylaxis counseling Infant feeding counseling
Prenatal visit 3	Initiation of ARV prophylaxis Individual counseling
Labor/Delivery	Intrapartum ARV component Avoidance of unnecessary invasive procedures/elective Caesarian Universal precautions
Post-partum	ARV prophylaxis for infant Support of infant feeding Family planning counseling Referral to support groups/follow-up
Infant follow-up	Growth and development monitoring HIV testing of baby Nutritional and infant feeding counseling Infections prevention/treatment Possible vaccination
Mother follow-up	OB/GYN and family planning services Primary care Individual counseling Coordination of care for the family

Table 1. Core components of the PMTCT case management monitoring database.

The case management database is composed of three different types of information: personal (e.g., name, date of birth, etc.), psychosocial (e.g., unsafe behavior), and clinical. The database manager receives patient data from a healthcare provider, who fills in a paper form with 34 questions, 31 reflecting each of the indicators and 3 additional questions: name, date of birth, and date of delivery. It takes approximately 30-60 minutes to fill out the paper form. In some cases, the database manager completes the paper form using the patient's hospital medical chart. Data accuracy is ensured by cross checking it with the patient's official medical chart. If the chart is incomplete, the database manager or healthcare provider must interview the patient and/or medical professional for clarification. Along with the database manager, AIHA staff check the accuracy of the information on a quarterly basis during on-site visits to Odessa.



Database interface in which information about the delivery is entered.



Database interface in which information about the newborn is entered.

To protect personal data, the database manager gives each patient a unique identification code and all personal information is stored in an isolated password-protected file, separate from the actual database. When the database manager receives additional data for a particular patient—including information from another clinic or service provider—the patient's identifier code is located using the patient's name and date of birth and new data is added to the corresponding record. For example, the database

manager makes monthly/quarterly contact with the pediatrician at the Oblast AIDS Center to receive follow-up data on babies born to HIV+ women. This data is then entered into the system.

In Odessa, the database manager is a medical doctor who was trained with the support of AIHA;¹² AIHA staff also provided content development assistance for the database. Appropriate OOH staff were trained by the database manager on the collection requirements of the monitoring system.

The medical director of the OOH Maternity Hospital and the database manager review MTCT results on a monthly and quarterly basis. Indicator trends are analyzed and any detected decrease in quality of care (compared to the previous month/quarter) is investigated; each incident of decline is examined to determine the reason for the outcome. Based on analysis, required interventions are developed (see section below).



Interface screen that lists some of the categories (see Table 2) for which the database program provides analysis.

The implementation of a PMTCT case-management monitoring database can present several challenges. Among them are the:

- availability of computers at maternity hospitals and AIDS Centers;
- computer literacy of medical personnel;
- establishment of proper lines of communication between institutions to exchange data on a regular basis; and
- incentives and time to maintain the database (some healthcare administrators see this task as an additional burden on already overloaded personnel).

Because of OOH's long-term partnership experience with AIHA and US healthcare institutions, the challenges were addressed effectively through the motivation of staff and use of innovative management approaches developed during more than a decade of cooperation.

USING PMTCT CASE MANAGEMENT MONITORING TO IMPROVE DELIVERY OF CARE

Use of the PMTCT case management monitoring system has facilitated the continuous improvement of services, resulting in the 75% decrease in the number of HIV-infected babies born to HIV+ women at OOH (from 24% in baseline group to 6% in PMTCT group as of 2003). These results have been demonstrated through an on-going, case-controlled study that compares and tracks the effectiveness of the +PMTCT+ Project (integrated into MCH services):

- The baseline group consists of 50 pairs of HIV+ women and their (50) babies who received care prior to the establishment of OOH's comprehensive PMTCT activities (1997-1999).
- The PMTCT group consists of 244 HIV+ women and their 246 babies who were "enrolled" in the program as they were admitted to OOH for prenatal care and delivery, beginning in 2002. Reported data is through March 30, 2004.

Other selected healthcare delivery improvement results are shown in Table 2. Results show an overall improvement of healthcare system performance as related to PMTCT.

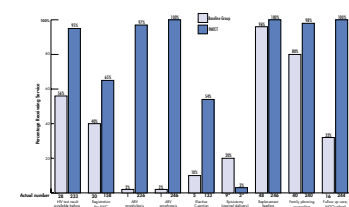


Table 2. Selected healthcare delivery improvements attributed to the implementation of the PMTCT case management monitoring system.

The on-going case management monitoring system enables medical and social service providers to analyze specific areas for improvement. For example, case management analysis conducted by maternity hospital staff showed that 3% of the women were non-compliant with medications due to their refusal to take antiretroviral (ARV) drugs and not because of a shortage of medication or lack of professional knowledge about how to provide antiretroviral therapy (ART). This conclusion demonstrated the need for community-oriented educational

programs to support adherence, particularly for vulnerable groups; these programs will begin later this year.

Case management analysis also showed that 5% of the HIV+ women admitted for delivery did not know their HIV status because they never received prenatal care and were members of vulnerable groups (mostly IDUs). This highlighted the need to continue to work closely with local NGOs on early identification and referral of HIV-infected pregnant women to PMTCT services. The Odessa team plans to further strengthen this component of their model by creating a task force whose members will consist of medical professionals and representatives of NGOs. The task force will work to develop specific activities aimed at reaching 100% of the HIV-infected pregnant women in the oblast and providing them with PMTCT services.

Results clearly demonstrate that the Odessa PMTCT case management monitoring system can be used to improve quality by measuring the effectiveness of MCH healthcare delivery during the prenatal, delivery, and postpartum periods, and for further follow-up care.

SCALE-UP OF PMTCT CASE MANAGEMENT MONITORING IN RESOURCE-LIMITED COUNTRIES

As a result of the demonstrated effectiveness of the PMTCT case management monitoring system in Odessa, in December 2003, the Ukrainian MOH mandated the development of a national PMTCT monitoring system based on the Odessa model. This national PMTCT monitoring database will be implemented at MCH institutions and AIDS Centers in all 26 oblasts of Ukraine. Data collected and analyzed at the oblast level will be transferred to the national level.¹¹

The scale-up of the Odessa case management database within Ukraine required the adaptation of indicators for nationwide use and the addition of a special codification section that protects confidential personal information (e.g., name, address, date of birth, etc.). As in the Odessa model, each patient is given a unique identifier that can be accessed by the database manager. In addition to protecting a patient's privacy, this identifier helps to avoid the loss or duplication of patient information that may be associated with women or children changing their place of residence or other factors. The Odessa database manager has developed a nationwide model that is currently being beta-tested and conducted on-site training for database users in each of the 26 oblasts. The first national reports will be available in late summer 2004.

Scale-up of the Odessa case management monitoring system is also taking place at AIHA PMTCT replication sites in Russia (Samara and Togliatti) and Kazakhstan (Almaty, Karaganda, Pavlodar, and Temirtau). This process includes adapting database indicators to the existing healthcare delivery system, on-site training of personnel, and the establishment of coordination and information exchange mechanisms among institutions involved in PMTCT. For example, local identification codes for healthcare personnel and other available standardized information were added to the Samara PMTCT case management monitoring system. To ensure the sustainability of the system, it is important that the database is integrated within any existing healthcare reporting systems.

CONCLUSIONS

By adapting internationally-accepted indicators and involving healthcare workers in the process, the PMTCT case management monitoring system has proven to be an effective and replicable model for measuring healthcare delivery and improving the quality of MCH services in resource-limited settings. Monitoring key indicators through a simple database enables providers to analyze specific fields for improvement and to demonstrate the impact on healthcare outcomes.

However, further development of the specific instruments to monitor the qualitative aspects of the program (e.g., reasons why women were "missed" by services, quality of HIV testing and counseling) is needed. Such instruments will complement the existing case-based management system to monitor PMTCT and will lead to further improvement of healthcare delivery to prevent HIV infection among infants and children.

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9. The program has been supported by USAID, Ukraine State Foundation (USF) - Boulder Community Hospital, the Odessa Oblast Health Administration, Odessa State Medical University, and other local and international NGOs, as well as the Ukrainian Ministry of Health.
10. WHO/UNICEF/UNAIDS, "Local Monitoring and Evaluation of the Integrated Prevention of Mother-to-Child HIV Transmission and Case-based Counseling," Draft March 2003.
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12. As part of a partnership program, AIHA establishes Learning Resource Centers at seven partner institutions to foster communication and access to information. In addition to providing computer, Internet access, and related equipment, the information and communication technology (ICT) program trains healthcare providers in evidence-based medical research, patient records management, and other areas related to the care and treatment of patients.

