



Findings of a Case Study of HIV Testing Policies in Practice

As of January 1, 2010, there were 182 000 cases of HIV infection registered in Ukraine, including 37 000 AIDS cases.¹ Since the beginning of the HIV/AIDS epidemic, there have been 21 000 deaths attributed to AIDS.² Experts estimate that approximately 360 000 individuals aged 15 and older are living with HIV,³ indicating that Ukraine has one of the highest HIV prevalence rates in Europe, encompassing 1.33% of the country's population. With increasing heterosexual transmission (45% of all transmissions in 2010),⁴ the proportion of HIV-positive people in Ukraine that are female has increased to 44%.⁵ In this context, Ukraine has adopted policies dictating routine HIV testing of women during antenatal care. While national policy provides for certain safeguards in the provision of HIV testing, including informed consent, counseling, and confidentiality, the degree to which these policies and the protection of women's rights are upheld in practice has not been well understood.

To explore these issues, HealthRight conducted a case study, between October 2009 and June 2010, of women's experiences with HIV testing during pregnancy in the Donetsk region, which has among the highest levels of HIV prevalence in Ukraine. The case study included (1) a qualitative research component of semi-structured interviews with 25 medical providers and 60 pregnant women who had been tested within the past 60 days; and (2) a more in-depth narrative collection component of interviews with 30 women about their experiences in the year following HIV testing during pregnancy.

Key findings from the qualitative research interviews with pregnant women include:

- *Informed consent* The majority of women (68%) reported that they filled out and signed a form to give consent for their HIV test. However, 18% of women reported giving only oral and not written consent, and a number of women did not have a clear understanding of what they were consenting to.
- *Voluntary testing* Despite these informed consent procedures, only 53% of the women understood that the test was voluntary; additionally, several women expressed a sense that they did not have a real choice about whether to test due to health provider practices.
- *Confidentiality* Nearly a quarter of women (23%) reported that their HIV testing or the subsequent reporting/use of results was conducted in conditions that violated their confidentiality. While the majority of women reported that they were not personally concerned about confidentiality, several of those who were HIV-positive discussed situations in which test results had been delivered via employers or shared by providers with other providers and/or patients.
- *Quality and content of counseling* The quality and content of counseling varied greatly among women interviewed. Only 20% of women were asked about their risk behaviors during pre-test counseling and only 5% were asked during post-test counseling. However, women reported being generally satisfied with the pre-test counseling they received. Post-test counseling was minimal among HIV-negative women. However, a number of the HIV-positive women reported being in

¹ Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #35, 2011

² Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #35, 2011

³ Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #34, 2010

⁴ Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #35, 2011

⁵ Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #35, 2011

shock upon receiving the results, and not being able to process much information regarding follow-up and referral.

- *Stigma/discrimination resulting from HIV status* Four of the seven HIV-positive women interviewed described experiencing stigma and discrimination in the health care setting as a result of their status. Three women reported being advised to terminate their pregnancies. Several women described observing or experiencing discriminatory and inhumane conduct during labor and delivery due to HIV status.
- *Payment for services* Some women reported being asked to pay for services or supplies that should have been free of charge related to their HIV testing during pregnancy.
- *Referrals* Only 53% of women were provided with information about local AIDS Centers and organizations working with PLWHA.

Key findings from qualitative research interviews with medical providers:

- *Informed consent, volunteer testing and confidentiality* For the most part, providers reported following practices to ensure informed consent, protect confidentiality, and provide counseling. Providers also expressed mixed feelings on whether it is ever appropriate to disclose a patient's HIV status to others.
- *Delivery of HIV test results* A number of providers (17%) expressed discomfort with their counseling role, particularly in having to deliver the news of a positive HIV test to a patient.
- *Resources* All providers reported having an inadequate amount of time to provide thorough counseling to patients during the HIV testing process, as well as a lack of appropriate information materials to distribute to patients.
- *Referrals* Medical providers from urban areas indicated that they do not know of organizations where HIV-positive women may be referred for further care and support. Medical staff from semi-urban locations were better informed about referral options.

Local context - injection drug use:

- Most providers reported that they had never encountered a drug-using woman at their clinic, which accords with the low uptake of antenatal care among women who use drugs.
- Medical providers displayed varying attitudes towards drug-using women, which in certain cases were extremely negative.
- Very few providers demonstrated an understanding of drug use, its treatment, as well as substitution therapy during pregnancy.

The longer-term narrative collection confirmed many of these findings.

Results of the above described research suggest that the majority of women were offered HIV counseling and testing in a way that met the minimum obligations of national policy. The differences between the longer-term narratives and the more recent interviews also suggest that practices around HIV testing and the treatment of HIV-positive pregnant women are continuing to improve in Ukraine. However, both sets of findings indicate that much more can be done to safeguard the rights of pregnant women during the HIV testing and follow-up process, and to ensure that HIV-positive pregnant women have access to support services to protect their health and wellbeing both during pregnancy and after delivery.

These findings indicate a need for improvements in service delivery, as well as advocacy to strengthen policy implementation and reduce stigma and discrimination in Ukraine.

The full study report is available on www.healthright.org.ua