

Women and HIV Testing: Policies, Practices, and the Impact on Health and Human Rights

HIV testing has rarely been higher on the global AIDS agenda, with the release of the UNAIDS/WHO Guidance on Provider-Initiated HIV Testing and Counseling in 2007 and a commitment to scale up testing in many countries. However, critical issues regarding the testing of women have yet to be addressed. As the UNAIDS/WHO Guidance recognizes, “[w]omen may be more likely than men to experience discrimination, violence, abandonment or ostracism when their HIV status becomes known” (§ 5).

A growing number of countries are implementing either opt-out provider-initiated testing for pregnant women or mandatory premarital testing without assessing the impact of these policies on women’s health or their human rights implications. This fact sheet provides basic information on how this testing is being carried out.

TESTING PREGNANT WOMEN

The UNAIDS/WHO Guidance on Provider-Initiated HIV Testing and Counseling recommends that antenatal, child-birth, and postpartum health services be a priority for the implementation of provider-initiated opt-out testing and counseling, and that HIV-negative women be tested as early as possible in each new pregnancy (§§ 4.2.2, 4.3.2). This recommendation aims to ensure access to HIV services and treatment for mothers and newborns.

Based on an assessment of 19 countries, all the national policies reviewed required consent as a condition of testing.

- ▶ Most policies do not make clear whether consent should be obtained before or after pre-test counseling.
- ▶ Two policies require that consent be in writing, and seven that it be verbal, while the rest do not specify how it should be obtained.
- ▶ Only India’s and Cambodia’s policies state that women should be advised of potential risks of testing before they consent.
- ▶ Only India’s policy states that clients should be told that refusing to take the test will not affect their access to services.

The policies all indicate that clients should be given some information prior to testing, and should receive individual post-test counseling sessions.

- ▶ Pregnancy-specific policies all indicate that counselors

should advise women about available resource to prevent mother-to-child transmission of HIV (PMTCT).

- ▶ Most policies also indicate that clients should be advised of the benefits of testing, the nature of HIV/AIDS, and how to prevent sexual transmission of HIV/AIDS.
- ▶ Only India’s and Cambodia’s policies address the risks of testing, and only India’s policy states that clients should be told that they can receive services even if they refuse testing.
- ▶ Policies vary on whether pre-test counseling should be conducted in groups or individually.

All of the policies address confidentiality except for China’s.

- ▶ A number of policies allow for information to be shared among health care workers without the consent of the person tested: Guyana, Haiti, Moldova, Russia, South Africa, Ukraine, Zambia, and Zimbabwe. India’s policy includes conflicting information, both stating that women should consent to their status being shared and that a health worker has a right to know a woman’s status.
- ▶ In Guyana, Kenya, Moldova, Tanzania, and Zimbabwe, HIV status can be shared with a sexual partner without the person’s consent.
- ▶ Cambodia’s policy includes information on a woman’s right to address a breach of confidentiality.

Most policies describe the need for and use of a common set of indicators to collect data on program implementation.

- ▶ The monitoring and evaluation information is generally focused on the collection of statistics on the uptake of testing rather than the counseling process, the reasons for refusing testing, the enforcement of human rights protections, or the aftermath of testing.
- ▶ A number of policies state that a woman who declines the first offer of testing will be repeatedly offered the test

throughout the duration of antenatal care, at the time of delivery, and immediately following delivery.

- ▶ Policies generally do not provide instructions for assessing why a woman is declining an offer of testing.
- ▶ For the most part, policies refer to “trained” or “certified” counselors. However, few documents identify the training needs of these individuals.
- ▶ Most policies state that referrals should be made to treatment and care for those testing positive. China, Kenya, and Uzbekistan are exceptions.

MANDATORY PREMARITAL TESTING

Mandatory premarital HIV testing refers to the requirement of an HIV test as a condition for entering into marriage. The International Guidelines on HIV/AIDS and Human Rights state, “it is clear that the right of people living with HIV is infringed by mandatory premarital testing and/or the requirement of ‘AIDS-free certificates’ as a precondition for the grant of marriage licenses under State laws.” This implicates the right to marry (Universal Declaration of Human Rights, Article 16, International Covenant of Civil and Political Rights, Article 23(2), Convention on the Elimination of All Forms of Discrimination against Women, Article 16(1)(a)).

Proponents of mandatory premarital testing have argued that it is an effective strategy to prevent HIV transmission in high prevalence areas and refer people to HIV treatment and care. Some claim a desire to protect women and children in developing countries, pointing out that younger women are often married off to older, sexually experienced men with little control over the choice of husband. Proponents of “abstinence until marriage” sometimes view premarital testing as a mechanism to discourage premarital sex.

Since the turn of the century, a growing number of Christian and Muslim communities have enforced mandatory premarital testing.

- ▶ In Nigeria in the late 1990s, Orthodox and Pentecostal churches began to require a mandatory premarital HIV test for those who wish to marry in the church. Reports of mandatory premarital testing among Catholic parishioners date back to 2000, and the Anglican Communion made mandatory testing a policy across all Anglican dioceses in Nigeria in 2000.
- ▶ In the Democratic Republic of Congo (DRC), the Communauté des Églises Baptistes au Centre de l’Afrique has made premarital testing mandatory since 1997, and the Commune Mayor’s Office has made premarital testing mandatory since 2004.
- ▶ Mandatory premarital testing in Malaysia began at the initiative of the Johor State Religious Department in November 2001. It has since become the policy of the religious departments in seven additional states and extends only to Muslim couples.
- ▶ In 2002, Protestant, Pentecostal, and Evangelical churches in Ghana implemented mandatory premarital testing for their congregations, but the churches soon backed

down to voluntary testing under criticism from the Ghana National Anti-AIDS Commission. However, social pressures have meant that the test de-facto remains mandatory, and everyone who marries in the church is expected to bring HIV test results.

- ▶ In Zanzibar, religious leaders began recommending premarital testing in 2002 and 2003, and although the test is not mandatory, effective religious lobbying in the community has rendered premarital testing a social expectation.
- ▶ In Burundi, mandatory premarital testing became official Catholic Church policy in 2006.
- ▶ In Uganda, by 2006, church leaders were requiring an HIV test of couples wishing to marry.

Governments are also increasingly adopting mandatory premarital testing.

- ▶ In 1994, seven out of Mexico’s 32 states required premarital HIV testing as part of a mandatory premarital screening package.
- ▶ In Cambodia, a high level discussion on the Implementing Guidelines of the 2003 HIV/AIDS Law found parental insistence on a premarital test to be consistent with this law.
- ▶ Since 2004, doctors in Uzbekistan are authorized to mandate an HIV test based on an evaluation of an individual’s risk and observations of symptoms.
- ▶ Reports from the southern Chinese province of Yunnan indicate that in January 2007, the regional government made premarital HIV testing mandatory in particular high prevalence areas.
- ▶ In India, the village council, or *panchayat*, of Budni in the southern state of Karnataka began mandating premarital testing in early 2007.
- ▶ In early 2008, Saudi Arabia announced that it would make premarital testing mandatory.

The results of mandatory premarital testing are often not kept confidential.

- ▶ In Burundi, DRC, Ghana, Malaysia, Nigeria, Uzbekistan, and Yunnan province in China prospective spouses are informed of each other’s status.
- ▶ In Cambodia, parents are permitted to attend the premarital testing session.
- ▶ Those undergoing mandatory premarital testing through Orthodox and Pentecostal churches in Nigeria must take the test under the supervision of a representative of the church marriage committee, and results are disclosed directly to the church prior to notification to the couple.
- ▶ In Baptist churches in the DRC, HIV test results are sent directly from the clinic to the head pastor who convenes a committee meeting at which the results are disclosed and discussed. After this, the couple is invited to a meeting in which they are informed of the results by the committee.
- ▶ In Johor, Malaysia, an official intention to marry is declared prior to undergoing HIV testing, and cancellation of marriage plans can lead to public suspicion of a positive result.

- ▶ Studies in China and Malawi have found that when HIV testing is a prerequisite for marriage, cancellations of marriage can lead the community to conclude that one or both of the parties is HIV-positive, and secrecy may no longer be possible to maintain.

Counseling services are often lacking in premarital testing environments.

- ▶ In Burundi, priests in Catholic churches which require premarital testing are not trained HIV counselors (2006).
- ▶ In Ghana, church-based marriage counselors report being ill-equipped to counsel members diagnosed as HIV-positive and have requested training and support from the government (2005).
- ▶ In Cambodia, a 2005 study found that post-test counseling generally lasted five minutes and that counselors did not address all risk behaviors.
- ▶ With the exception of Malaysia, none of the communities or institutions adopting mandatory premarital testing made explicit provision for services linked to premarital testing.
- ▶ Services in Malaysia consisted of counseling from the state religious department (and in some states the health department) which generally advises discordant couples not to marry.

The United States experimented with premarital HIV testing briefly in the late 1980s.

- ▶ More than 30 states considered premarital testing, but only the two states of Illinois and Louisiana actually enacted and enforced mandatory premarital testing statutes.
- ▶ In 1988, Louisiana identified two HIV-positive marriage license applicants, putting the average cost of one HIV-positive identification at \$70,000-\$85,000.
- ▶ In Illinois, the number of marriages registered in the state declined, while numbers in adjacent states increased.
- ▶ Louisiana repealed its statute seven months after enacting it, and Illinois after twenty months.

Experiences with premarital testing have revealed limitations to its effectiveness in preventing the spread of HIV.

- ▶ A 1993 study of mandatory premarital testing in the Mexican province of Coahuila concluded that mandatory premarital testing was “useless in the control of the spread of HIV as refusal of a license to marry does not prevent sexual activity among consenting adults.”
- ▶ A growing number of studies suggest that women are most vulnerable to HIV infection in the context of their marriages, and not just before marriage. Studies in Africa find that married women have a higher rate of infection than sexually active unmarried women, and according to the United Nations Population Fund, 60 to 80 percent of HIV-positive women in sub-Saharan Africa have been infected by their husbands, their sole partner. A 2005 study in Cambodia determined that 43 percent of all new infections occurred between husband and wife, and a similar 2007 Uganda study revealed that two thirds of

people living with HIV were married. According to the 2004-2005 Uganda national survey, 18 percent of married men and three percent of married women had engaged in extramarital sex in the proceeding year and only half of them had practiced safe sex. Moreover, practices such as polygyny provide a social sanction for men to look outside marriage for new partners and sexual fulfillment.

- ▶ There is concern that mandatory premarital testing will not assist vulnerable populations, such as sex workers and people who use drugs. These groups are particularly concerned about their status and fearful of exposure, and may avoid being tested. Studies from China and Malawi indicate that fears about compromised confidentiality lead those most vulnerable to infection to eschew premarital testing.
- ▶ There appears to be a growing industry in fake HIV certificates showing a false negative status. Cases of couples offering fake HIV certificates have been documented in Burundi and Malaysia.

POTENTIAL RISKS FOR WOMEN

HIV testing can carry risks for women, including violence and stigma. Rates of non-disclosure are especially high among women seeking antenatal care. According to the Pan American Health Organization, not only are pregnant women more vulnerable and economically dependent, but pregnancy is a period of particularly high-risk for violence. Fearful of these risks, women tested may not disclose their HIV status to their partners. According to one study, an average of 71 percent of women in the developed world and only 52 percent of women in the developing world share their HIV status with their partners.

Pregnant women who test positive for HIV may be subjected to abuse or discrimination by partners or health care providers.

- ▶ In studies in sub-Saharan Africa and Southeast Asia, between 3.5 to 14.6 percent of women reported a violent reaction from their partner following disclosure of their HIV status.
- ▶ In another study, women in sub-Saharan Africa reported negative outcomes upon HIV status disclosure, including blame, stigmatization, violence, abandonment, and loss of economic support.
- ▶ In a study in India, 12 out of 52 women who disclosed their results to their partner were beaten or abused by their in-laws, and 18 of 52 were no longer allowed to do housework.
- ▶ Research in Russia reveals forced abortion to be another major risk of prenatal HIV tests.

Premarital HIV tests can also result in negative outcomes.

- ▶ Positive HIV status precludes marriage in Budni in India (2007) and in the Mexican states where premarital testing is mandated (1994).
- ▶ The Baptist churches in the DRC (2007) and the Orthodox and Pentecostal churches in Nigeria (2006)

do not allow discordant couples to marry.

- ▶ In Ghana and Malaysia, discordant couples are counseled not to marry.
- ▶ In Saudi Arabia, positive cases are referred to the Ministry of Justice.

These risks have been shown to deter women from disclosing their HIV status, thus impeding access to treatment for women and their children.

- ▶ In one study in sub-Saharan Africa, 77.8 percent of HIV-positive women failed to share their status with their partners even after 18 months of follow up.
- ▶ A clinic in Zambia, which provides free antiretrovirals for women who test HIV-positive, reported that over 60 percent of eligible women refuse treatment because of fears of violence and abandonment upon partner disclosure.
- ▶ In a recent Zambian study, 75 percent of 560 HIV-positive women participants were unable to adhere to ARV regimens because they were trying to hide pills or were forced to share medication with an untested spouse. According to UNAIDS statistics, 89 percent of pregnant HIV positive women are not receiving PMTCT, and 530,000 children are infected.

INTERNATIONAL LAW

International human rights law protects women's right to physical integrity, including consensual treatment and freedom from violence, under the rights to life, health, equality, and freedom from cruel, inhuman, and degrading treatment (Universal Declaration of Human Rights, Articles 3, 5, 7, 25; International Covenant of Civil and Political Rights, Articles 6(1), 7, 26; International Covenant on Economic, Social and Cultural Rights, Article 12(1); Convention on the Elimination of All Forms of Discrimination against Women, Articles 2(e), 15(1)).

Women's rights in regard to HIV testing are protected in a number of international statutes and laws.

- ▶ Access to crucial pre- and post-test information is protected by the right to information (Universal Declaration of Human Rights, Article 19, International Covenant of Civil and Political Rights, Article 9(2)).
- ▶ Consent to HIV testing and confidentiality of HIV status are key components of the right to privacy (Universal Declaration of Human Rights, Article 12, International

Covenant of Civil and Political Rights, Article 17(1)). As the International Guidelines on HIV/AIDS and Human Rights clarify, "The right to privacy encompasses obligations to respect physical privacy, including the obligation to seek informed consent to HIV testing and privacy of information, including the need to respect confidentiality of all information relating to a person's HIV status" (para. 119). Thus, under Guideline 3, "HIV testing of individuals should only be performed with the specific informed consent of that individual" (para. 20(b)).

- ▶ A right of access to HIV testing itself is part of the right to health (International Covenant on Economic, Social and Cultural Rights, Article 12). As the United Nations Committee on Economic, Social and Cultural Rights explained, "The prevention, treatment and control of epidemic...diseases requires the establishment of prevention and education programmes for behaviour-related health concerns..., in particular HIV/AIDS" (General Comment 14, para. 16). The International Guidelines on HIV/AIDS and Human Rights specify that state obligations under the right to health include "ensuring access...to voluntary and confidential testing with pre-and post-test counseling" (para. 144).
- ▶ The International Guidelines on HIV/AIDS and Human Rights further recognize the need for "a supportive and enabling environment for women...and other vulnerable groups by addressing underlying prejudices and inequalities through...specially designed social and health services and support to community groups" (Guideline 8, para. 60). They specifically recommend: "Legal and support services should be established to protect individuals from any abuses arising from HIV testing" (para. 38). The UNAIDS/WHO Guidance on Provider-Initiated HIV Testing and Counseling likewise stresses the need to accompany provider-initiated testing with an enabling environment, or a package of prevention, treatment, care, and support services (§ 5).

FOR MORE INFORMATION, SEE:

Maman S., Groves A., King E., Pierce M., Wyckoff S. *HIV testing during pregnancy: A literature and policy review—background paper*. New York, USA: Open Society Institute, 2008 (forthcoming).

Burns, K. *Premarital HIV testing—background paper*. New York, USA: Open Society Institute, 2008 (forthcoming).

To view the fact sheet with footnotes please visit www.soros.org/health

Law and Health Initiative

The Law and Health Initiative (LAHI) of the Open Society Institute's Public Health Program promotes legal action to advance public health goals worldwide. LAHI supports legal assistance, litigation, and law reform efforts on a range of health issues, including patient care, HIV and AIDS, harm reduction, palliative care, sexual health, mental health, and Roma health. LAHI's priorities include integrating legal services into health programs, strengthening human rights protections within health settings, and developing training and education programs in law and health. A special focus is on supporting organizations and advocacy campaigns dedicated to ending human rights abuses linked to the global AIDS epidemic. By bringing together legal, public health, and human rights organizations, LAHI seeks to build a broad movement for law-based approaches to health and for the human rights of society's most marginalized groups.