

## Human Immunodeficiency Virus\*

### Committee on Ethics

**ABSTRACT:** Because human immunodeficiency virus (HIV) infection often is detected through prenatal and sexually transmitted disease testing, an obstetrician–gynecologist may be the first health professional to provide care for a woman infected with HIV. Universal testing with patient notification and right of refusal (“opt-out” testing) is recommended by most national organizations and federal agencies. Although opt-out and “opt-in” testing (but not mandatory testing) are both ethically acceptable, the former approach may identify more women who are eligible for therapy and may have public health advantages. It is unethical for an obstetrician–gynecologist to refuse to accept a patient or to refuse to continue providing health care for a patient solely because she is, or is thought to be, seropositive for HIV. Health care professionals who are infected with HIV should adhere to the fundamental professional obligation to avoid harm to patients. Physicians who believe that they have been at significant risk of being infected should be tested voluntarily for HIV.

Between 1 million and 1.2 million individuals in the United States are estimated to be living with human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) (1). Women represent the fastest-growing group of individuals with new HIV infections (2). Many women who are infected with HIV are not aware of their serostatus (3).

Human immunodeficiency virus often is diagnosed in women during prenatal antibody screening or in conjunction with screening for sexually transmitted diseases (STDs). Because many women initially identified as infected with HIV are not aware that they have been exposed to HIV and do not consider themselves to be at risk, universal testing with patient notification is more effective than targeted, risk-based testing in identifying those who are infected with HIV (4). The tension between competing goals for HIV testing—testing broadly in order to treat the maximum number of women infected with HIV and, if pregnant, to protect their newborns, and counseling thoroughly in order to maximally protect a woman’s autonomy and right to participate in decision making—has sparked considerable debate.

Because HIV infection often is detected through prenatal and STD screening, it is not uncommon for an obstetrician–gynecologist to be the first health professional to provide care for an infected woman. This Committee Opinion is designed to provide guidance to obstetrician–gynecologists regarding ethical issues associated with HIV testing, including the use of newly developed rapid HIV tests and disclosure of positive test results. It also outlines responsibilities related to patient care for women who are infected with HIV, access for affected couples to assisted reproductive technology, and the health care professional who is infected with HIV.

### Human Immunodeficiency Virus Counseling and Testing

The major ethical principles that must be considered when formulating policies for HIV counseling and testing include respect for autonomy, confidentiality, justice, protection of vulnerable individuals, and beneficence to both the woman tested and, if she is pregnant, to her newborn as well. Individuals offering testing need to be mindful not only of the benefits of testing but also its potential risks because, if a woman’s test result is positive, she faces the possibility of being ostrac-



**The American College  
of Obstetricians  
and Gynecologists**

*Women’s Health Care  
Physicians*

\*Update of “Human Immunodeficiency Virus” in *Ethics in Obstetrics and Gynecology*, Second Edition, 2004.

cized by her family, friends, and community or being subjected to intimate partner violence. In addition, although the overt stigma of HIV infection has been reduced over the past 20 years, the potential for job discrimination, loss of health insurance, and loss of housing still exists.

Over time, three potential strategies for HIV testing have been considered by public health and public policy officials: 1) universal testing with patient notification and right of refusal, also called “opt-out” testing; 2) voluntary testing with pretest counseling regarding risks and benefits, also called “opt-in” testing; and 3) mandatory testing with no right of refusal. In order to understand their ethical merits, each is considered briefly in the sections that follow. Increasingly, national organizations and federal agencies have recommended opt-out testing in preference to other strategies.

### **Universal Testing With Patient Notification and Right of Refusal—Opt-Out Testing**

Opt-out testing removes the requirement for pretest counseling and detailed, testing-related informed consent. Under the opt-out strategy, physicians must inform patients that routine blood work will include HIV testing and that they have the right to refuse this test. The goal of this strategy is to make HIV testing less cumbersome and more likely to be performed by incorporating it into the routine battery of tests (eg, the first-trimester prenatal panel or blood counts and cholesterol screening for annual examinations). In theory, if testing barriers are reduced, more physicians may offer testing, which may lead to the identification and treatment of more women who are infected with HIV and, if pregnant, to the prevention of mother-to-infant transmission of HIV. This testing strategy aims to balance competing ethical considerations. On the one hand, personal freedom (autonomy) is diminished. On the other hand, there are medical and social benefits for the woman and, if she is pregnant, her newborn from identifying HIV infection. Although many welcome the now widely endorsed opt-out testing policy for the potential benefits it confers, others have raised concerns about the possibility that the requirement for notification before testing will be ignored, particularly in today’s busy practice environment. Indeed, the opt-out strategy is an ethically acceptable testing strategy only if the patient is given the option to refuse testing. In the absence of that notification, this approach is merely mandatory testing in disguise. If opt-out testing is elected as a testing strategy, a clinician must notify the patient that HIV testing is to be performed. Refusal of testing should not have an adverse effect on the care the patient receives or lead to denial of health care. This guarantee of a right to refuse testing ensures that respect for a woman’s autonomy is not completely abridged in the quest to achieve a difficult-to-reach public health goal.

### **Voluntary Testing With Pretest Counseling Regarding Risks and Benefits—Opt-In Testing**

Voluntary testing with counseling is the strategy most consistent with respect for patient autonomy. Under this option, physicians provide both pretest and posttest counseling. Some physicians may perform such counseling themselves, whereas others may prefer to refer the patient for counseling and testing. (Such specialized HIV counseling was more widely available in previous years but has become less available as more health care professionals have become more comfortable treating patients with HIV and as the opt-out approach to testing—an approach that places less emphasis on pretest counseling—has become more common.) In addition to medical information, such counseling could include information regarding potential uses of test information and legal requirements pertaining to the release of information. Patients should be told what information will be communicated and to whom and the possible implications of reporting the information. This approach to testing maintains HIV’s status as being in a class by itself (*sui generis*), even as many ethicists have acknowledged the end to the exceptionalism that marked this disease in the early years of the epidemic (5).

### **Mandatory Testing With No Right of Refusal**

Mandatory testing strategies are problematic because they abridge a woman’s autonomy. In addition, during pregnancy, the public health objective of this strategy, identification of women who are infected with HIV who will benefit from treatment, has been accomplished in certain populations by other ethically sound testing strategies noted previously (6). Some see mandatory testing as a more efficient way of achieving universal testing. Advocates support this strategy, believing it provides the greatest good for the greatest number and that the potential benefit to the woman and, if pregnant, her newborn justifies abridging a woman’s autonomy. However, because of the limits it places on autonomy, the Committee on Ethics believes that mandatory HIV screening without informing those screened and offering them the option of refusal is inappropriate. Mandatory prenatal testing is difficult to defend ethically and has few precedents in modern medicine, although HIV testing of newborns is now required in New York, Connecticut, and Illinois (There are provisions, however, that permit refusal in a few defined circumstances.) (7, 8). Importantly, mandatory testing may compromise the ability to form an effective physician–patient relationship at the very time when this relationship is critical to the success of treatment.

### **Selecting a Testing Strategy**

Among these three strategies, the opt-out approach is now recommended by most national organizations and federal agencies. For prenatal HIV testing, universal testing with patient notification and right of refusal was recommended by the Institute of Medicine to address

clinicians' concerns that pretest counseling and informed consent mandates for routine voluntary testing in pregnancy were too time consuming and, thus, reduced the likelihood of testing being offered (9). The Centers for Disease Control and Prevention, the American Academy of Pediatrics, and the American College of Obstetricians and Gynecologists (ACOG) endorse this approach (10, 11). Evidence suggests that this strategy may be acceptable to many pregnant women (12, 13). "To expand the gains made in diagnosing HIV infection among pregnant women," the Centers for Disease Control and Prevention (14) has recently released, and ACOG (15) has adopted, recommendations to make HIV testing a "routine part of medical care" using a similar opt-out approach for all women at the time of routine health care visits.

In recommending the opt-out approach for prenatal HIV testing, ACOG encouraged Fellows to include counseling as a routine part of care but not as a prerequisite for, or barrier to, prenatal HIV testing (11). Similarly, the American Medical Association, in recommending that universal HIV testing of all pregnant women with patient notification of the right of refusal be a routine component of prenatal care, indicated that basic counseling on HIV prevention and treatment also should be provided to the patient, consistent with the principles of informed consent (16). Accordingly, if adopting this option, physicians should be prepared to provide both pretest and posttest counseling. Broad implementation of an opt-out strategy, however, will require changing laws in states that require detailed and specific counseling and consent before testing. Physicians should be aware of the laws in their states that affect HIV testing. The National HIV/AIDS Clinicians' Consultation Center at the University of California—San Francisco maintains an online compendium of state HIV testing laws that can be a useful resource (see <http://www.ucsf.edu/hivcntr/>).

The benefits of identifying those with HIV infection will be limited if necessary treatments are unavailable or not covered by appropriate insurance. Where access to HIV treatment is limited, Fellows should advocate for changes in existing policies to broaden access.

### **Special Issues Involved With Rapid Human Immunodeficiency Virus Testing**

Technologies have recently become available that allow for testing with rapid results (eg, turnaround less than 1 hour). The advantage of these tools is that patients can be informed of their results at the same visit at which the testing occurs. In that manner, it is possible to lower the rate of loss to follow-up associated with the traditional two-stage testing and notification approach. Nothing about rapid testing precludes the need for a patient to opt-in or to be offered the opportunity to opt-out of testing (depending on which strategy is adopted). Rapid testing should not be implemented either as mandatory

testing or testing performed without informing the patient that she will be tested.

In communities with a relatively low prevalence of HIV, rapid testing can present certain logistic difficulties. With the traditional approach, testing would occur during an initial visit, and results would be provided during a follow-up encounter. That would give the health care professional an opportunity to arrange for an individual with expertise in posttest counseling to be available in a circumstance in which the health care professional knew that a patient was returning to receive a positive result. A program of testing and notification at the same visit does not allow the health care professional the luxury of notifying a counselor before a patient who is infected with HIV returns for a visit or of steering an individual who is infected with HIV to a certain session at which the counselor is routinely available. However, the obligation to make sure that appropriate counseling and support services are available still holds. Health care professionals should develop links with individuals who can provide those services on an emergent basis or train their own staff to handle the initial encounter and thereafter transition infected individuals to professionals who can serve as ongoing resources to them.

### **Human Immunodeficiency Virus Reporting and Partner Notification**

The clinician providing care for a woman who is infected with HIV has important responsibilities concerning disclosure of the patient's serostatus. Clinicians providing health care should be aware of and respect legal requirements regarding confidentiality and disclosure of HIV-related clinical information.

In considering disclosure, clinicians may have competing obligations: protecting the patient's confidentiality, on the one hand, and disclosing test results to prevent substantial harm to a third party, on the other. In some jurisdictions, a breach of confidentiality may be required by mandatory reporting regulations. Even absent legal requirements, in some situations the need to protect potentially exposed third parties may seem compelling. In these situations, the clinician first should educate the patient about her rights and responsibilities and encourage her to inform any third parties involved. If she remains reluctant to voluntarily share information regarding her infection, consultation with an institutional ethics committee, a medical ethics specialist, or an attorney may be helpful in deciding whether to disclose her HIV status. In general, a breach of confidentiality may be ethically justified for purposes of partner notification when all of the following four conditions are met:

1. There is a high probability of harm to the partner.
2. The potential harm is serious.
3. The information communicated can be used to prevent harm.

4. Greater good will result from breaking confidentiality rather than maintaining it.

Indeed, many if not all of these conditions are likely met for intimate partners of women and men who are infected with HIV. Nevertheless, when a breach of confidence is contemplated, practitioners should weigh the potential harm to the patient and to society at large. Negative consequences of breaking confidentiality may include the following situations:

- Personal risks to the individual whose confidence is breached, such as serious implications for the patient's relationship with family and friends, the threat of discrimination in employment and housing, intimate partner violence, and the impact on family members
- Loss of patient trust, which may reduce the physician's ability to communicate effectively and provide services
- A ripple effect among cohorts of women that may deter other women at risk from accepting testing and have a serious negative impact on the educational efforts that lie at the heart of attempts to reduce the spread of disease

If, on balance, a breach of confidence is deemed necessary, practitioners should work in advance to anticipate and manage potentially negative consequences (ie, reactions of intimate partners, family). As well, practitioners should consider whether the goal of maintaining patient privacy would be better served by personal communication with the individual placed at risk by the patient's seropositivity or by notification of local public health authorities. In some areas, anonymous notification of sexual contacts is possible through local or state departments of health. As a practical matter, because disclosure is only possible when the index case freely identifies at-risk partners, superseding an individual's refusal to disclose should be a rare occurrence.

Confidentiality should not be breached solely because of perceived risk to health care workers. Health care workers should rely on strict observance of standard precautions rather than obtaining information about a patient's serostatus to minimize risk. Even in the setting of an accidental needle-stick or other exposure, the patient's consent for release of serostatus (or for testing) should be obtained. Efforts to protect patient confidentiality should not prevent other health care professionals caring for the patient from learning her serostatus, information they need to ensure optimal medical management.

### **Health Care Professionals' Obligation to Provide Care**

It is unethical for an obstetrician-gynecologist to refuse to accept a patient or to refuse to continue providing health care for a patient solely because she is, or is thought to be, seropositive for HIV. Refusing to provide care to

women who are infected with HIV for fear of contracting HIV infection or simply as a practice preference is unreasonable, unscientific, and unethical.

Epidemiologic studies have shown that the risk of HIV transmission from patient to health care professional is exceedingly low and is related to needle stick or intraoperative injury or to potentially infectious fluid that comes in contact with a mucous membrane (17). Most contacts between health care professionals and women who are infected with HIV occur, however, during routine obstetric and gynecologic care. Health care practitioners should observe standard precautions with all patients to minimize skin, mucous membrane, and percutaneous exposure to blood and body fluids to protect against a variety of pathogens, including HIV.

Health care professionals who fail to provide care to women who are infected with HIV because of personal practice preferences violate professional ethical standards. The public appropriately expects that health care practitioners will not discriminate based on diagnosis, provided that the patient's care falls within their scope of practice. Physicians should demonstrate integrity, compassion, honesty, and empathy. Failure to provide health care to a woman solely because she is infected with HIV violates these fundamental characteristics. As with any other patient, it is acceptable, however, to refer women who are infected with HIV for care that the physician is not competent to provide or if care elsewhere would be more convenient or associated with decreased financial burden to the patient.

### **Assisted Reproductive Technology**

There is an emerging consensus that indications for assisted reproductive technology use should not vary with HIV serostatus; therefore, assisted reproductive technology should be offered to couples in which one or both partners are infected with HIV. This approach is consistent with the principles of respect for autonomy and beneficence (18, 19). In addition, those who advocate providing these services cite three clinical arguments to support their position:

1. Therapeutic improvements in the management of HIV infection have enhanced both quality and length of life for individuals who are seropositive for HIV.
2. Advances in prenatal therapy have substantially reduced the risk of mother-to-infant HIV transmission.
3. Current assisted reproductive technology methods may reduce transmission of HIV from an infected partner to an uninfected partner relative to natural means of conception.

The Ethics Committee of the American Society for Reproductive Medicine has said, "Health care workers who are willing to provide reproductive assistance to cou-

ples whose offspring are irreducibly at risk for a serious genetic disease should find it ethically acceptable to treat HIV-positive individuals or couples who are willing to take reasonable steps to minimize the risks of transmission.” (20).

Those who oppose offering these technologies to couples who are infected with HIV cite two major objections:

1. Uncertain long-term parental prognosis
2. The continuing risk of mother-to-infant HIV transmission

The ethical underpinning of this opposition is that it is not felt to be in the best interest of the child to be born to a parent who may not be available for continued child-rearing. In addition, the risk of mother-to-infant transmission places the infant at risk of acquiring a highly debilitating illness. Yet as stated previously, HIV infection currently is a manageable chronic illness with a life-expectancy equivalent to that with many other chronic diseases for which assisted reproductive technology is not routinely precluded. Further, interventions, such as anti-retroviral therapy or cesarean delivery or both, reduce the absolute risk of transmission to a level comparable, again, to risks significantly lower than those tolerated among couples choosing assisted reproductive technology (eg, parents who are carriers of autosomal recessive conditions) or risks often assumed as part of assisted reproductive technology (eg, risks of prematurity from multiple pregnancies).

### **Health Care Professionals Who Are Infected With Human Immunodeficiency Virus**

In making decisions about patient care, health care professionals who are infected with HIV should adhere to the fundamental professional obligation to avoid harm to patients. Physicians who have reason to believe that they have been at significant risk of being infected should be tested voluntarily for HIV for the protection of their patients as well as for their own benefit. The physician as a patient is entitled to the same rights to privacy and confidentiality as any other patient.

Although the risk of clinician-to-patient transmission is extremely low, all infected physicians must make a decision as to which procedures they can continue to perform safely. This decision primarily will depend on the particular surgical technique involved and also on the physician’s level of expertise and medical condition, including mental status. The clinician’s decision should be made in consultation with a personal physician and may possibly involve such other responsible individuals as the chief of the department, the hospital’s director of infectious diseases, the chief of the medical staff, or a specialized advisory panel. If physicians avoid procedures that place patients at risk of harm, they have no obligation

to inform the patient of their positive HIV serostatus. Physicians who are infected with HIV should follow standard precautions, including the appropriate use of hand-washing, protective barriers, and care in the use and disposal of needles and other sharp instruments.

### **Recommendations**

The Committee on Ethics makes the following recommendations:

- All women, pregnant or not, should have the opportunity to learn their HIV serostatus.
- Women should, at a minimum, be told that they are being tested and that they may refuse such tests.
- Although opt-out and opt-in testing are both ethically acceptable, the former approach may identify more women who are eligible for therapy and may have public health advantages.
- Rapid testing carries the same ethical responsibilities as “standard” testing.
- It is unethical for an obstetrician–gynecologist to refuse to accept a patient or to discontinue providing health care for a patient solely because she is, or is thought to be, seropositive for HIV.
- Seropositivity for HIV per se should not be used as a reason to refuse to provide assisted reproductive technology to a family.

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Human immunodeficiency virus. ACOG Committee Opinion No. 389. American College of Obstetricians and Gynecologists. *Obstet Gynecol* 2007;110:1473–8.

12345/10987

ISSN 1074-861X