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Minister of Public Works and Government Services Canada, 2002  
Cat. No. H39-619/2002  
ISBN0-662-66535-X

# Guiding Principles for the HIV Testing of Women During Pregnancy

Prepared by  
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A subcommittee of  
the Federal/Provincial/Territorial Advisory Committee on  
Population Health

March 2002

# Background

Since 1994, when it became evident that the antiretroviral drug zidovudine (AZT) was effective in reducing the rate of perinatal HIV transmission, provinces and territories have been developing, refining and implementing policies on HIV testing during pregnancy.

The common principles of voluntarism, confidentiality and informed consent have guided policy development at the federal, provincial and territorial levels with respect to HIV testing in general. These principles are consistent with, and in some cases identical to, recommendations made as early as 1989 by the National Advisory Committee on AIDS<sup>1</sup> and repeated more recently by others.<sup>2-4</sup> This document serves as a reminder that these principles should also apply to policy development regarding HIV testing of women during pregnancy.

The goals of HIV testing during pregnancy are threefold to: identify women who are HIV-positive so that they can receive optimal medical and psychosocial care for themselves; decrease the incidence of mother-to-child transmission of HIV; and, reduce the risk of transmission to sexual partners.<sup>2</sup> Offering HIV testing during pregnancy is therefore an important component of good prenatal care.

Current testing technology and treatment options have made it possible to prevent virtually all mother-to-child transmission of HIV.<sup>5</sup> Therefore, the identification and appropriate management of HIV infection in pregnancy is even more important. However, in some jurisdictions, there is evidence that almost half of pregnant women are not tested for HIV.<sup>6</sup> Furthermore, of those pregnant women who are tested, in some cases it is done without their knowledge. For these reasons, it is important to reiterate that the principles of voluntarism, confidentiality and informed consent should guide policy and practices for the prevention of mother-to-child HIV transmission. The intent is not to be prescriptive, but rather to ensure these widely supported principles continue to guide the refinement and development of relevant policy.

# Principles

The principles presented in this document are equally relevant to guiding HIV testing policies in general as to guiding policies related to HIV testing during pregnancy. They serve to acknowledge that a woman does not give up her rights as an individual because she is pregnant.

## Offering Testing to Every Pregnant Woman

Difficulties arising from undertaking risk assessment as a prerequisite to offering HIV testing to a pregnant woman include, but are not limited to, the following:

- ◆ Cohort and case control studies have shown that targeted testing limited to pregnant women with identifiable risk factors will identify only 8-58% of those who are HIV- positive.<sup>2</sup>
- ◆ “A study of positive women found that 90% had no perception of risk before testing positive.<sup>8</sup>
- ◆ Evidence suggests that many women who believe that they are involved in monogamous relationships are at risk of HIV due to their partner’s past or ongoing risk activity.<sup>8</sup>
- ◆ Some women are exposed to risk factors that health care providers may not be aware of, including unprotected anal intercourse, the use of powders or astringents to induce vaginal drying and female genital mutilation.<sup>8</sup>
- ◆ Anecdotal and qualitative evidence suggests that women may be discouraged by their physician from testing for HIV because of a perceived absence of risk factors.<sup>9</sup>

## Testing must be voluntary

According to the Code of Ethics of the Canadian Medical Association,<sup>7</sup> it is a fundamental principle in health care that a patient has the right to accept or refuse proposed care. Guidelines for the HIV testing of women during pregnancy acknowledge a woman’s right to be tested for HIV during pregnancy to ensure that she can seek and receive care for herself and her child. According to the National Advisory Committee on HIV/AIDS:

“In order to facilitate HIV antibody testing, to avoid potential harm while seeking the greatest benefits from HIV antibody testing, and to minimize the likelihood of coercion, voluntary testing should be the preferred approach.”<sup>1</sup>

Voluntary testing is consistent with voluntary treatment, as the decision to receive antiviral treatment during pregnancy remains a voluntary decision under Canadian law.<sup>4</sup> Voluntary testing also maintains women's confidence in their relationship with their physician.<sup>4</sup> Evidence suggests that when physicians present women with the risks and benefits of antiviral treatment for preventing vertical transmission, most women accept testing and treatment.<sup>7</sup>

## Informed Consent

In order to perform a treatment, diagnostic or medical procedure on a patient, a health care practitioner must, among other things, obtain the informed consent of the person to this treatment, diagnostic or procedure. The Supreme Court of Canada (SCC) has set out the minimum requirements for obtaining informed consent. In addition, some provinces have passed legislation regarding informed consent. The SCC noted that before consent can be considered informed, certain information must be disclosed to the patient prior to medical treatment. This is essentially information about the treatment, such as its seriousness, any material risks and any unusual or special risks, even if they are only a possibility; answers to the patient's questions about the risks related to the treatment; information that the doctor should know is relevant to that particular patient; information that a reasonable patient, in the same circumstances, would want to know; information provided in such a way that the doctor is confident the patient has understood.<sup>10-11</sup>

The Code of Ethics of the Canadian Medical Association, sections 12-15,<sup>7</sup> suggests the following practices for physicians when proposing a course of treatment or testing:

- ◆ *“Provide your patients with the information they need to make informed decisions about their medical care, and answer the questions they have to the best of your ability.*
- ◆ *Make every reasonable effort to communicate with your patients in such a way that information exchanged is understood.*
- ◆ *Recommend only those diagnostic and therapeutic procedures that you consider to be beneficial to your patient or to others. If a procedure is recommended for the benefit of others, as for the benefit of public health, inform your patient of this fact and proceed only with the explicit informed consent or where required by law.*
- ◆ *Respect the right of a competent patient to accept or reject any medical care recommended.”*

Pre-test counselling of pregnant women has led to higher acceptance rates of testing, increased knowledge of HIV transmission and increased use of condoms and contraceptives.<sup>2</sup> Case-controlled studies have shown that the length of time spent counselling and the individual counsellor involved are the strongest predictors of who will accept testing.<sup>2</sup> Information can come from a variety of sources, for example, distributed written materials, videotapes, referrals to hotlines or AIDS service organizations, or one-on-one conversations with health care professionals. Information should be geared to the audience, taking into account such things as linguistic and cultural barriers, geographic isolation, lack of transportation and child care, and fear of punitive action (for example, if involved in drug use).

### **Testing should maintain confidentiality**

Confidentiality is important in the provision of health care services in order to respect the dignity of the patient and to ensure candour in patient-health care practitioner relationships. Confidentiality is particularly important in the case of HIV testing because of the stigma and discrimination faced by persons at high risk for or living with HIV/AIDS.<sup>4</sup>

Evidence suggests that fear of punitive or discriminatory actions following a disclosure of HIV or injection-drug-using status may deter women from coming forward for HIV testing and/or other prenatal services.<sup>9</sup>

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