

PROVIDER-INITIATED HIV TESTING AND COUNSELING IN HEALTH FACILITIES – WHAT DOES THIS MEAN FOR THE HEALTH AND HUMAN RIGHTS OF PREGNANT WOMEN?

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Keywords

HIV/AIDS,
ethics,
antiretroviral therapy,
gender,
rights,
health

ABSTRACT

Since the introduction of drugs to prevent vertical transmission of HIV, the purpose of and approach to HIV testing of pregnant women has increasingly become an area of major controversy. In recent years, many strategies to increase the uptake of HIV testing have focused on offering HIV tests to women in pregnancy-related services. New global guidance issued by the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) specifically notes these services as an entry point for provider-initiated HIV testing and counseling (PITC). The guidance constitutes a useful first step towards a framework within which PITC sensitive to health, human rights and ethical concerns can be provided to pregnant women in health facilities. However, a number of issues will require further attention as implementation moves forward. It is incumbent on all those involved in the scale up of PITC to ensure that it promotes long-term connection with relevant health services and does not result simply in increased testing with no concrete benefits being accrued by the women being tested. Within health services, this will require significant attention to informed consent, pre- and post-test counseling, patient confidentiality, referrals and access to appropriate services, as well as reduction of stigma and discrimination. Beyond health services, efforts will be needed to address larger societal, legal, policy and contextual issues.

The health and human rights of pregnant women must be a primary consideration in how HIV testing is implemented; they can benefit greatly from PITC but only if it is carried out appropriately.

INTRODUCTION

As the HIV epidemic continues to grow, women are increasingly and disproportionately affected. HIV prevalence among women now exceeds half of the total prevalence in many countries particularly where the disease is generalized.¹ For many years, however, interventions that focused on increasing women's access to prevention, treatment and care were not prioritized. Since the discovery in 1994 that administration of zidovudine (also known as AZT) to HIV positive women during pregnancy greatly reduced the likelihood of mother-to-child transmission of HIV,² prevention of mother to child transmission (PMTCT) programs began to be instituted globally and pregnant women have been a focus population for HIV testing. As new anti-retroviral drugs became available, the standard of care, where available, usually became the administration of a combination of three highly active antiretrovirals.³ In part due to available technologies, the focus of these programs was primarily on preventing infection among newborns and less, or not at all, on the care and treatment women would need to cope with their own disease. As the claims of advocates have been increasingly heard and additional antiretroviral therapies have been developed, a number of PMTCT programs have incorporated long-term care and treatment of women (and, in some cases, their partners) into their services (PMTCT+).⁴ Thus, pregnancy-related services, including antenatal care, delivery and post-partum services, constitute an important entry point for HIV testing. Nonetheless, current

evidence suggests that in developing countries only 9% of women requiring access to PMTCT services actually receive them.⁵ Access to PMTCT+ is even more limited.

Despite agreement on the need to scale up HIV testing, considerable debate persists about how to do this most effectively and what the implications of scale up are for different populations in different contexts.⁶ Strategies to increase the uptake of HIV testing have often focused on the provision of an HIV test to women in pregnancy-related services without clear attention to how this can best be done. Documentation of the processes and outcomes of different strategies remains insufficient.

Global policy statements until recently promoted only client-initiated voluntary counseling and testing (VCT) within and outside of health care settings, insisting on what were termed 'the three Cs': consent, counseling and confidentiality.⁷ Despite its value in both public health and human rights terms, many now claim that this is a necessary but insufficient approach to HIV testing. A number of practitioners have called for approaches to scaling up HIV testing in health care settings that would make HIV testing more 'routine'.⁸ While generally well-intentioned, these unfocused calls left ambiguity in how 'routine' testing approaches, evaluated against both public health and human rights criteria, would, or should, play out in practice.

In August 2006, in an attempt to provide some direction, the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) issued a statement in which they promoted provider-initiated HIV testing and

¹ World Health Organization (WHO)/Joint United Nations Programme on HIV/AIDS (UNAIDS). 2006. *AIDS Epidemic Update 2006*. Geneva: WHO/UNAIDS. Available at: http://www.unaids.org/en/HIV_data/epi2006/ [Accessed 18 Sept 2007].

² E.M. Connor et al. Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment. Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. *N Engl J Med* 1994; 331: 1173–1180.

³ World Health Organization (WHO). 2006. *Antiretroviral Therapy of HIV Infection in Infants and Children: Towards Universal Access. Recommendations for a Public Health Approach*. NLM classification: WC 503.2. Geneva: WHO. Available at: <http://www.who.int/hiv/pub/guidelines/art/en/index.html> [Accessed 18 Sept 2007].

⁴ L. Myer et al. Focus on Women: Linking HIV Care and Treatment with Reproductive Health Services in the MTCT-Plus Initiative. *Reprod Health Matters* 2005; 13: 136–146.

⁵ World Health Organization (WHO)/Joint United Nations Programme on HIV/AIDS (UNAIDS). 2007. *Children and AIDS: A Stock-taking Report*. Geneva: WHO/UNAIDS/UNICEF. Available at: <http://www.who.int/hiv/mediacentre/news64/en/> [Accessed 18 Sept 2007].

⁶ M.J. Heywood. The Routine Offer of HIV Counseling and Testing: A Human Right. *Health Hum Rights* 2005; 8(2): 13–19.

⁷ World Health Organization (WHO)/Joint United Nations Programme on HIV/AIDS (UNAIDS). 2004. *Policy Statement on HIV Testing*. Geneva: WHO/UNAIDS. Available at: <http://www.who.int/hiv/pub/vct/en/hivtestingpolicy04.pdf> [Accessed 18 Sept 2007].

⁸ M.A. Stoto, D.A. Almaro & M.C. McCormick, eds. 1999. *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States*. Washington, DC: National Academy Press; K. De Cock, D. Mbori-Ngacha & E. Marum. Shadow on the Continent: Public Health and HIV/AIDS in Africa in the 21st century. *Lancet* 2002; 360(9326): 67–72.

counseling (PITC) in health facilities.⁹ A few months later they released global guidance on PITC in health facilities.¹⁰

Looking closely at the WHO/UNAIDS guidance, we seek to highlight some issues relevant to assuring the health and rights of pregnant women in the context of PITC, making particular note of areas where further attention may be needed to clarify roles and responsibilities within the health system, and ultimately to ensure that pregnant women receive the services they require.

Structured around some of the key elements of PITC relevant to pregnant women where ethics and human rights issues come into play, the following sections present existing evidence, outline briefly how each issue is addressed within the guidance, and propose areas where further attention is required. These analyses are focused on resource-poor countries with generalized HIV epidemics, even as many of the same considerations may be relevant to concentrated epidemics. The paper concludes by underscoring the need to ensure that good public health practice is promoted in a manner consistent with ethics and human rights.

WHO/UNAIDS GUIDANCE ON PROVIDER-INITIATED HIV TESTING AND COUNSELING IN HEALTH FACILITIES

The WHO/UNAIDS guidance has the stated purpose of scaling up PITC to ensure ‘the timely detection of HIV, prevention of HIV transmission, and subsequent access to appropriate HIV prevention, treatment, care and support services.’¹¹ In order to achieve this, the guidance strives for

⁹ World Health Organization (WHO)/Joint United Nations Programme on HIV/AIDS (UNAIDS). 2006. *WHO and UNAIDS Secretariat Statement on HIV Testing and Counseling*. Geneva: WHO/UNAIDS. Available at: http://data.unaids.org/pub/ExternalDocument/2007/20070905_rghr_statement_testing_en.pdf [Accessed 18 Sept 2007].

¹⁰ World Health Organization (WHO)/Joint United Nations Programme on HIV/AIDS (UNAIDS). 2007. *Guidance on Provider-initiated HIV Testing and Counselling in Health Facilities*. NLM classification: WC 503.1. Geneva: WHO/UNAIDS. Available at: http://www.who.int/hiv/who_pitc_guidelines.pdf [Accessed 18 Sept 2007].

¹¹ Ibid: 30.

‘synergy between medical ethics, clinical, public health and human rights objectives.’¹² It specifically recommends that, in generalized HIV epidemics (parts of sub-Saharan Africa, Asia, Central America and the Caribbean), antenatal, childbirth and postpartum health services should be some of the most important health facilities for the implementation of PITC (see Box 1).

The guidance is careful to highlight the need for adaptation to every country context, including:

an assessment of the risks and benefits of introducing provider-initiated HIV testing and counseling in a particular setting, including an appraisal of available resources, prevailing standards of HIV prevention, treatment, care and support and the social, legal and policy framework that is in place.¹³

What constitutes an acceptable balance of risks and benefits for implementing PITC will vary by country, by community, and by population.

As with all guidance documents that are global in remit, the language is designed to be sufficiently general to be applicable in all settings. Yet, this lack of specificity suggests that additional consideration of certain issues is needed as HIV testing policies and practice are developed and, particularly in the case of pregnant women, the ways in which differentials in gender, age, and other factors should be addressed.

IMPLICATIONS OF PITC FOR PREGNANT WOMEN IN HEALTH FACILITIES

There is general consensus that HIV testing strategies should be centered around the best interests of the individual patient which, according to the guidance, ‘requires giving individuals sufficient information to make an informed and voluntary decision to be tested, maintaining patient confidentiality, performing post-test counselling and making referrals to appropriate services.’¹⁴ While this statement suggests promotion of good health outcomes, respect

¹² Ibid: 18.

¹³ Ibid: 17.

¹⁴ Ibid: 6.

Box 1. PITC and Pregnancy-related Services

In generalized epidemics, WHO and UNAIDS recommend PITC for all adults in health facilities irrespective of their reason for seeking services. However, there is recognition that in light of resource constraints prioritization of sites for implementation of PITC will be required and it is recommended that antenatal, childbirth and postpartum health services be one priority location for implementing PITC. Several points are made regarding PITC within these services:

- (1) PITC should be carried out as early as possible during pregnancy;
- (2) PITC is recommended for 'all women of unknown HIV status in labour or, if this is not feasible, as soon as possible after delivery';
- (3) PITC should be provided to women in the postpartum period;
- (4) Antiretroviral prophylaxis and infant feeding counseling should be an integral part of the package of care;
- (5) Support should be provided to women who test negative to prevent them becoming infected during the course of their pregnancy; and
- (6) Women should be counseled to encourage their partners to seek HIV counseling and testing.

In concentrated and low-level epidemics, antenatal, childbirth and postpartum services are locations where delivery of PITC can be considered based upon assessment of the epidemiological and social context. The guidance states that all women attending these services should receive information on mother to child transmission and HIV testing.

See World Health Organization (WHO)/Joint United Nations Programme on HIV/AIDS (UNAIDS). 2007. *Guidance on Provider-initiated HIV Testing and Counselling in Health Facilities*. Geneva: WHO/UNAIDS.

for human rights, and assurance of an ethical testing process, what it means in reality for different populations, in particular when a woman is pregnant, highlights why specific attention must be given to this population as programs are developed.¹⁵

Contrast the following two scenarios:

- (1) An employed, middle class man goes voluntarily to a provider's office for an unrelated health issue and is offered an HIV test; and
- (2) A poor woman goes to a health service because she is about to deliver a baby and is offered an HIV test.

It is likely that the power differential between doctor and patient is much greater in the second of these scenarios. What are the opportunities for explanation and rational decision-making that exist in each case? It is worth considering in each case what steps will be taken to ensure informed consent is assured, the ways in which pre- and post-test counseling will be provided, and how each person will be informed of a positive test result, in addition to how the confidentiality of the result will be assured.¹⁶

A woman is likely to access health services when pregnant or during childbirth and consequently this is an opportune time for offering HIV counseling and testing. Yet it cannot be assumed that, even if PMTCT is available, all pregnant women will choose to undergo HIV testing. Recent studies have shown a relatively high uptake of HIV testing when offered as part of antenatal care services where PMTCT services were available, ranging from 70–97%.¹⁷ This nonetheless means that, despite the availability of PMTCT services, 3–30% of women

¹⁵ C. Smith et al. Should Rapid Tests for HIV Infection Now be Mandatory During Pregnancy? Global Differences in Scarcity and a Dilemma of Technological Advance. *Developing World Bioeth* 2007; 7: 86–103.

¹⁶ M. de Bruyn & S. Paxton. HIV Testing of Pregnant Women – What is Needed to Protect Positive Women's Needs and Rights? *Sex Health* 2005; 2: 143–151; A.H. Fisher, C. Hanssens & D.I. Schulman. The CDC's Routine HIV Testing Recommendation: Legally, Not so Routine. *HIV AIDS Policy Law Rev* 2006; 11(2–3): 17–20.

¹⁷ L. Tsague et al. 2005. *Can We Scale Up National Prevention of Mother-to-Child Transmission Program in Low Resources Settings? Lessons Learned and Challenges from Cameroon's Experience*. Abstract of presentation at 3rd annual IAS conference on Pathogenesis and Treatment. Rio de Janeiro, 24–27 July. Available at: <http://www.ias-2005.org/planner/Abstracts.aspx?AID=2381> [Accessed 4 Oct 2007]; M. Temmerman et al. Mother-to-child Transmission of HIV in Resource Poor Settings: How to Improve Coverage? *AIDS* 2003; 17: 1239–1242.

declined to be tested for HIV. Reasons given by women for refusing the HIV test include: fear of the test itself, fear of the consequences of a positive test result, knowledge that antiretroviral therapy (i.e. longer-term treatment for the woman herself) is not available, and the need to consult her partner before testing.¹⁸ These factors can outweigh concerns related to perinatal transmission of HIV. While counseling may serve to allay some of these concerns, a pregnant woman must, ultimately, be allowed to evaluate the information available to her and come to her own conclusion regarding whether or not she wishes to undergo testing. This is critical for ensuring that women retain trust in health services, including in relation to engagement with any prevention, care and treatment services that might be required by the woman and the newborn in the longer-term. This is, after all, ostensibly the primary purpose of making HIV testing available. Not only is this a cornerstone of human rights and the ethical provision of health care, it is fundamental to good public health.

Issues where further clarification may be required for national-level implementation of testing strategies based on the new guidance are noted below.

(i) Pre-test counseling

Pre-test counseling is vital for pregnant women to ensure that they understand the implications of a negative or positive test result, for themselves, their partners and any future children. It is also an opportunity to provide prevention information to those who do not have frequent access to health services.¹⁹ The primary concern of women accessing pregnancy-related services is likely to be that their pregnancy be safe and healthy. Without appropriate pre-test counseling, they may be mentally unprepared to undergo HIV testing let alone to receive a positive test result. Entirely eliminating pre-test counseling or providing insufficient information minimizes the opportunities for ensuring informed

consent and potentially makes receiving a positive test result more difficult to deal with.²⁰

Once a key component of HIV testing, pre-test counseling is now minimized in the PITC guidance and ‘an HIV test is recommended as a standard part of the patient’s medical care’.²¹ Pre-test counseling has been replaced with ‘simplified pre-test information’ and, although a minimum standard exists with respect to the information that must be included, when this should be done and how long it should take requires explicit attention.

(ii) Informed consent

In many settings, culture dictates that patients, and especially female patients, do not question the medical advice of their doctor. Thus, without adequate strategies to ensure informed consent, the opportunity to decline testing will remain beyond the reach of many pregnant women. The reasons why patients fail to oppose the recommendations of their health care provider include the high social status ascribed to medical professionals, the belief that a doctor might react negatively to such a decision and that this might negatively impact on health care provision, and the perception of HIV testing as something that has been institutionally sanctioned and is therefore the ‘right’ thing to do.²² A study in Botswana, where HIV testing is routinely ‘offered’, showed that 68% of participants believed that they could not refuse the test.²³ While there is no disaggregation of this figure by population group, one can reasonably assume that women’s self-perceived inability to refuse an HIV test will be further exacerbated by gender dynamics that make it difficult for women to say no in this context.²⁴

²⁰ E. Joo et al. Implementation of Guidelines for HIV Counseling and Voluntary HIV Testing of Pregnant Women. *Am J Public Health* 2000; 90: 273–276.

²¹ World Health Organization/Joint United Nations Programme on HIV/AIDS, *op. cit.* note 10, p. 5.

²² S. Rennie & F. Behets. Desperately Seeking Targets: The Ethics of Routine HIV Testing in Low-income Countries. *Bull World Health Organ* 2006; 84: 52–57.

²³ S.D. Weiser et al. Routine HIV testing in Botswana: A Population-based Study on Attitudes, Practices and Human Rights Concerns. *PLoS Medicine* 2006; 3: e261.

²⁴ C. Worthington & T. Myers. Factors Underlying Anxiety in HIV Testing: Risk Perceptions, Stigma, and the Patient-Provider Power Dynamic. *Qual Health Res* 2003; 13: 636–655.

¹⁸ J. Kowalczyk et al. Voluntary Counseling and Testing for HIV among Pregnant Women Presenting in Labor in Kigali, Rwanda. *J Acquir Immune Defic Syndr* 2002; 31: 408–415.

¹⁹ F. Perez et al. Prevention of Mother to Child Transmission of HIV: Evaluation of a Pilot Programme in a District Hospital in Rural Zimbabwe. *BMJ* 2004; 329: 1147–1150.

In deciding to undergo HIV testing, a pregnant woman must take into account not only the health of her baby but also her own health, the potential social implications of a positive test result, and her own prospects for accessing treatment, care and support services. Thus, in order to make an informed decision to be tested, a pregnant woman needs to know why HIV testing is being offered, how it will be carried out, what to anticipate the implications of her results will be, and whether or not she will be able to access treatment for both PMTCT and lifelong antiretroviral therapy, as well as other care and support services, if she were to need them. The WHO/UNAIDS guidance lists all of these issues as topics to be discussed with patients, but the concrete steps that would need to be taken in order for this to become possible require specific consideration.

Issues surrounding informed consent during delivery are particularly complicated, especially in relation to women who present at health services when they are already in labor. While many women will be perfectly capable of assimilating information and making a truly informed decision regarding whether or not to undergo HIV testing in the throes of labor, others may be physically or mentally constrained in their ability to process the range of issues necessary for ensuring true informed consent. The guidance clearly states that 'HIV testing and counselling should be recommended to all women of unknown HIV status in labour or, if this is not feasible, as soon as possible after delivery.'²⁵ Eliciting informed consent is one of the criteria that must be satisfied before testing can be performed during labor, as in all other circumstances; if the woman's ability to provide informed consent is in any way impaired, testing should not be carried out, but how to ensure this in practice is not clear.

Informed consent is an area of debate of particular relevance to pregnant women. Guidance is limited, even from the human rights regime. The Committee that monitors the Convention on the Elimination of All Forms of Discrimination Against Women has asserted that women have a right to 'be

fully informed, by properly trained personnel, of their options in agreeing to treatment or research.'²⁶ However, even as testing where treatment is available is covered by this statement, provision is not made for circumstances where treatment is not available – as will be the case in most places where the guidance is implemented. Two recent studies from the United Kingdom found an incompatibility between ensuring informed oral consent and 'routine' HIV testing in antenatal care.²⁷ Although testing uptake appeared to increase when routinely offered, an erosion in meeting criteria to ensure informed consent also appeared to be occurring.

The WHO/UNAIDS guidance recommends verbal communication as an adequate means for obtaining informed consent but further evidence is needed on the implications of this practice in different contexts and for different groups. How can informed consent rather than mere acquiescence be orally ensured for a woman in the context of childbirth? This issue will need to be carefully monitored going forward to ensure that both health and rights are sufficiently protected.

While pregnant women are themselves a vulnerable population in this context, additional areas of concern are raised with respect to consent when the pregnant woman is an adolescent.²⁸ In places where legal frameworks require parental consent before HIV testing can be made available, efforts will be needed to reconcile differences between law and practical realities. Recognizing the health and rights of young women as the paramount consideration will offer some guidance. Some additional support

²⁵ World Health Organization/Joint United Nations Programme on HIV/AIDS, *op. cit.* note 10, p. 23.

²⁶ United Nations. Office of the High Commissioner for Human Rights (UNHCHR) 1999. *Women and Health: 05/02/99. CEDAW General recom. 24. (General Comments). Women and Health.* New York, NY: UNHCHR: Paragraph 20. Available at: [http://www.unhchr.ch/tbs/doc.nsf/\(symbol\)/CEDAW+General+recom.+24.En?OpenDocument](http://www.unhchr.ch/tbs/doc.nsf/(symbol)/CEDAW+General+recom.+24.En?OpenDocument) [Accessed 18 Sept 2007].

²⁷ R. Bennett. Routine Antenatal HIV Testing And Informed Consent: An Unworkable Marriage? *J Med Ethics.* 2007; 33: 446–448; P. de Zulueta & M. Boulton. Routine Antenatal HIV Testing: The Responses and Perceptions of Pregnant Women and the Viability of Informed Consent. A Qualitative Study. *J Med Ethics* 2007; 33: 329–336.

²⁸ J.A. Singh et al. Enrolling Adolescents in Research on HIV and Other Sensitive Issues: Lessons from South Africa. *PLoS Med* 2006; 3: e180; D.A. Murphy et al. Adolescent Medicine HIV/AIDS Research Network. Factors Associated with HIV Testing among HIV-positive and HIV-negative High-risk Adolescents: The REACH Study. *Pediatrics* 2002; 110: e36.

is provided by the Committee on the Rights of the Child. In particular, the General Comment on Adolescent Health stipulates that 'if the adolescent is of sufficient maturity, informed consent shall be obtained from the adolescent her/himself.'²⁹ While once again the focus is on ensuring informed consent for treatment, this provision is useful in its clarity with respect to the need to engage specifically with the adolescent, even in the face of opposing legal or cultural norms. These issues are complex and discussion will be needed in any program going forward to ensure that no room is left for misinterpretation.

(iii) Post-test counseling

Counseling is not simply a human rights imperative: it is a medical intervention that is vital to support pregnant women with prevention efforts, disclosure, living with a life-threatening virus, and adherence to treatment.³⁰ The WHO/UNAIDS guidance highlights post-test counseling as an 'integral component of the HIV testing process'³¹ and something that everyone should receive irrespective of their test result. For women who are tested during labor, the question arises as to when the test result should be disclosed and post-test counseling provided – During labor? As soon as the child is born? In the context of being told the child's status? As PITC is rolled out, explicit attention to these issues will be required, in both implementation and monitoring and evaluation, to ensure the systematic provision of quality care.

(iv) Referrals and access to appropriate services regardless of the test result

From the perspectives of public health, ethics and human rights, there is an obligation to ensure that if

testing is performed, pregnant women's access to care and treatment is not only a theory but a duly implemented practice. Explicit connections between testing services and long-term access to appropriate HIV- and health-related services, with due attention to the individual's right to privacy, must be set forth in as much detail as possible. In the case of pregnant women, this includes services for both the mother and, assuming that she chooses to carry her pregnancy to term, her child. It is critical that testing be implemented as a necessary step in the process of linking women to the health services they require, and not be relegated simply to testing for testing's sake.

Facilitating access to appropriate services following PITC is one of the stated aims of the new guidance. WHO insists that for PITC to be effective, patients need to be 'offered or referred to appropriate follow-up services';³² however, how best to guarantee this in resource-constrained settings, for the population generally and for pregnant women specifically, remains to be determined. At a minimum, in order to ensure that people receive the services they need, immediate investment in referral systems is imperative. Furthermore, indicators will be needed that capture, alongside the uptake of testing, the strength of the linkages with long-term prevention, care and treatment services for women in the context of pregnancy, childbirth and beyond.

(v) Patient confidentiality

How best to maintain privacy and confidentiality, both critical components of the long-term management of HIV illness, must be carefully considered in scaling up PITC for pregnant women. A pregnant woman may well be accompanied by relatives, including her male partner, at the health facility; if she tests positive, efforts must be made to ensure she has the space and time to come to terms with her diagnosis and its potential implications, both immediate and longer-term, with the support of health professionals and without the engagement of any relatives she has not chosen to bring into this process. This is a particularly acute situation if testing takes place during labor and is of course

²⁹ United Nations. Convention on the Rights of the Child. 2003. *Adolescent Health and Development in the Context of the Convention on the Rights of the Child: 01107/2003. CRC/GC/2003/4. (General Comments)*. New York, NY: UN. Available at: [http://www.unhcr.ch/tbs/doc.nsf/\(symbol\)/CRC.GC.2003.4.En?OpenDocument](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/CRC.GC.2003.4.En?OpenDocument) [Accessed 17 Sept 2007].

³⁰ M. Heywood. The Routine Offer of HIV Counseling and Testing: A Human Right. *HIV AIDS Policy Law Rev* 2006; 11: 71–72.

³¹ World Health Organization/Joint United Nations Programme on HIV/AIDS, *op. cit.* note 10, p. 10.

³² *Ibid*: 30.

further complicated where the patient herself is still legally considered a minor. The WHO/UNAIDS guidance repeatedly states the need to protect the confidentiality of an HIV test result, but step by step practical direction is required on how this can be assured, particularly in resource-constrained settings. Health care professionals have themselves often been responsible for direct breaches of confidentiality.³³ They will have to be trained, and the physical infrastructure of health care facilities will have to be improved to allow for private consultations between patients and health care providers. This will require not only good will but significant financial resources.

The guidance refers to 'ethical partner notification', which UNAIDS has previously defined to involve 'strong and professional efforts to encourage, persuade and support HIV-positive persons to notify and counsel partners.'³⁴ When a positive person refuses to notify their partner of their HIV status:

the health care provider should be able to counsel partners, without the consent of the source client, after there has been an ethical weighing of the potential harms involved, and appropriate steps have been taken.³⁵

Importantly, women in antenatal settings appear to be least likely of any population to choose to disclose their status to partners, which likely relates to fear of stigma, discrimination and violence.³⁶ Although the importance of disclosure of HIV status to partners and relatives is clear, pregnant women's risk of adverse outcomes from disclosure

can not be ignored.³⁷ It has been reported that physical violence as a result of disclosure occurs in many settings and disproportionately affects women.³⁸ It is incumbent upon all those providing HIV testing services to ensure that safeguards are in place to protect people, and especially pregnant women, from such negative outcomes. In the situation where a positive woman does not wish to notify her partner of her status, an enormous responsibility is placed on health care providers who must decide whether or not, going against the wishes of the woman, the partner should be notified of her HIV status. Not only does this place health care providers in an ethically difficult situation, but it points to an area where significant effort to determine good practice will be needed in any scaling up of PITC.

(vi) Stigma and discrimination

It appears women are more likely than men to experience stigma associated with HIV.³⁹ Stigma and discrimination remain two of the most challenging barriers to implementation of HIV programs generally, and permeate health care services. This is especially pertinent for pregnancy-related services as reports of judgmental attitudes on the part of service providers with regard to positive women generally, and with respect to their desire to have children, abound from all corners of the world.⁴⁰

There is overt acknowledgement in the WHO/UNAIDS guidance that stigma and discrimination must be addressed not only within health services but also more broadly. Given that women, and especially pregnant women, use health services more frequently than men, they are often diagnosed with

³³ V. Datye et al. Private Practitioners' Communications with Patients around HIV Testing in Pune, India. *Health Policy Plan* 2006; 21: 343–352.

³⁴ Joint United Nations Programme on HIV/AIDS (UNAIDS). 2000. *Opening Up The HIV/AIDS Epidemic: Guidance on Encouraging Beneficial Disclosure, Ethical Partner Counselling, And Appropriate Use of HIV Case-Reporting*. Geneva: UNAIDS: 7. Available at: http://data.unaids.org/Publications/IRC-pub05/JC488-OpenUp_en.pdf [Accessed 18 Sept 2007].

³⁵ Ibid: 7.

³⁶ A. Medley et al. Rates, Barriers and Outcomes of HIV Serostatus Disclosure among Women in Developing Countries: Implications for Prevention of Mother-to-Child Transmission Programmes. *Bull World Health Organ* 2004; 82: 299–307.

³⁷ World Health Organization (WHO). 2004. *Gender Dimensions of HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes*. Geneva: WHO. Available at: <http://www.who.int/gender/documents/en/genderdimensions.pdf> [Accessed 17 Sept 2007].

³⁸ S. Maman et al. Women's Barriers to HIV-1 Testing and Disclosure: Challenges for HIV-1 Voluntary Counselling and Testing. *AIDS Care* 2001; 135: 595–603.

³⁹ United Nations. *Declaration of Commitment on HIV/AIDS: Five Years Later. Report of the Secretary General. Sixtieth Session. Agenda item 45. Follow-up to the outcome of the twenty-sixth special session: implementation of the Declaration of Commitment on HIV/AIDS*. Document A/60/736. New York, NY: UN. Available at: <http://www.un.org/Docs/journal/asp/ws.asp?m=A/60/736> [Accessed 17 Sept 2007].

⁴⁰ V. Paiva et al. The Right to Love: The Desire for Parenthood among Men Living with HIV. *Reprod Health Matters* 2003; 11: 91–100.

HIV before their male partners and therefore risk being blamed for bringing HIV into the relationship, even in situations where their partners may have contracted the virus first.⁴¹ Without proper support, PITC may inadvertently exacerbate a woman's risk of stigma from her partner, family and community.⁴² Recent research suggests that couples counseling may serve to alleviate some of the stigma experienced within a couple, but, even as many health service providers think this is a good idea, they feel ill-equipped to provide it.⁴³

As PITC is scaled up in health facilities generally and in pregnancy-related services in particular, it is important that health service providers be sensitized to these issues and that systems be instituted to protect pregnant women from any stigma and discrimination that may result from a positive HIV test, including opportunities for redress where this might be required.

ENSURING AN ENABLING ENVIRONMENT

In addition to the key issues related to the processes surrounding HIV testing, raised above, the implementation of PITC should be accompanied by the provision of a minimum package of HIV services. While there is no universally agreed-upon minimum package, the WHO/UNAIDS guidance proposes one set of services that should be considered, ranging from making condoms available to the provision of antiretroviral therapy where available.⁴⁴ This is a useful list, even as, in some places, significant time and investment will be required to determine not only which services can be made immediately available, but what efforts will be needed going forward to ensure constant improvement over time simply to deliver the minimum package.

⁴¹ A. Kmietowicz. Women are Being Let Down in Efforts to Stem HIV/AIDS. *BMJ* 2004; 328: 305.

⁴² Rennie & Behets, *op. cit.* note 27.

⁴³ H. Khan et al. Horizons Report: Operations Research in HIV/AIDS. 2006. *Initiating HIV Diagnostic Testing and Counseling: Study in Kenya Underscores Need for Adequate Training of Health Providers*. Washington, DC: Population Council. Available at: [https://www.popcouncil.org/horizons/newsletter/horizons\(13\)_2.html](https://www.popcouncil.org/horizons/newsletter/horizons(13)_2.html) [Accessed 20 Sept 2007].

⁴⁴ World Health Organization/Joint United Nations Programme on HIV/AIDS, *op. cit.* note 10, p. 31.

Attention to the larger social, policy and legal context relevant to the lives of pregnant women will maximize the positive value of scaling up PITC. Paying attention to laws and policies *outside* the health sector that may impact on testing uptake and connection to health services for pregnant women, such as required reporting of injecting drug users, may prove useful.⁴⁵ For example, if a woman who injects drugs becomes pregnant, even if she knows of the availability of PMTCT services, let alone PITC, she may choose not to access these services for fear of being reported to the authorities for illegal drug use. Prior to introduction of PITC services for pregnant women, a review should be carried out of the legal and policy environment in which services are provided, and, where it appears that utilization by vulnerable populations will be impeded, legal and policy reform should be effected so as to ensure that services are truly available to all those who might need them.⁴⁶

Accountability is also critical: local and national level policy makers have a responsibility to ensure that policy is developed to support best practice and that no practice goes unguided by policy. Continuous dialogue and channeling of lessons learned from experience are critical to ensuring that the approach taken to HIV testing is, and remains, appropriate. There is a need for transparent processes involving a mix of policy makers, practitioners and community representatives, and clear lines of accountability as the scaling up of PITC in pregnancy-related facilities moves forward.

Government actors and other policy-makers have a responsibility for providing the infrastructure for sustainable prevention, care and treatment programs, and for creating a climate in which pregnant women will want to know their HIV status and trust health care providers to provide them with both the necessary information and concomitant support. With health workers already grossly overstretched, finding the time and resources for these extra

⁴⁵ C.L. Galletly & S.D. Pinkerton. Conflicting Messages: How Criminal HIV Disclosure Laws Undermine Public Health Efforts to Control the Spread of HIV. *AIDS Behav* 2006; 10: 451–461.

⁴⁶ Joint United Nations Programme on HIV/AIDS (UNAIDS) Reference Group on HIV and Human Rights. *Criminalization of HIV Transmission*. Geneva: UNAIDS. Available at: http://data.unaids.org/pub/BaseDocument/2006/070216_HHR_3_Criminalization.pdf [Accessed 12 Sept 2007].

safeguards, let alone this extensive training, will be a definite challenge, even as it is desperately needed. Without concrete plans of how the required capacity building of health workers can be carried out, there is a danger that PITC will be rolled out before staff are adequately trained to provide the quality of services required by public health, ethics and human rights.

The question then becomes how to make certain that adequate attention is paid to ensuring that these requirements are met as PITC is implemented. The first step in implementation in any setting ought to be to assess how many of these prerequisites are already fulfilled and then to develop a plan for ensuring that the remaining requirements, including sufficient capacity building of health care professionals, can be put in place. This risks delaying implementation of PITC by many months or years in locations where it has not yet been implemented, and raises questions regarding what should be done where PITC is already being implemented without the necessary safeguards being in place. While there is an urgent need to scale up HIV testing, these issues must be adequately considered as testing strategies are put into place.

The goals of any HIV testing policy will most certainly affect how it is implemented and which components of the HIV testing process are emphasized. Monitoring and evaluation are vital to ensure that effective public health, ethical and human rights standards are met. Assuming the primary purpose of HIV testing is to link people to the services they require over time, any monitoring and evaluation of PITC needs to keep this long-term goal in mind. Differences of opinion exist as to whether PMTCT constitutes sufficient 'treatment' for a pregnant woman who tests positive to justify PITC, or whether an HIV positive diagnosis must also mean that the woman has access to the antiretroviral therapy she requires. Monitoring women's long-term engagement with the health services offered after a positive diagnosis can be a useful step in determining the effectiveness of PITC strategies being put into place.

CONCLUSION

The need to scale up HIV testing is beyond doubt, and the offer of PITC to pregnant women in health facilities presents a potentially important mechanism to contribute to this goal. As it stands, the WHO/UNAIDS guidance indicates that pregnant women will be one of the primary groups targeted by PITC activities. While this goal is not inappropriate, ethical, public health and human rights obligations require that special attention be paid to the vulnerabilities of this population, and that the sorts of issues noted above be taken into account by donors, national level governments, health care providers, affected communities and other partners going forward.

The guidance is clear:

Positive outcomes are most likely when HIV testing and counselling is confidential and is accompanied by counselling and informed consent, staff are adequately trained, the person undergoing the test is offered or referred to appropriate follow-up services and an adequate policy and legal framework is in place to prevent discrimination.⁴⁷

It is incumbent on all those involved in implementation of PITC to ensure that this spirit remains central and that the health and human rights of vulnerable populations are promoted and not put at risk. Pregnant women, due to their level of interaction with health services, and the priority given to pregnancy-related services in the scaling up of PITC, could be negatively affected if this mandate is not followed; conversely, they stand to benefit enormously from increased access to needed services if it is.

⁴⁷ World Health Organization/Joint United Nations Programme on HIV/AIDS, *op. cit.* note 10, p. 30.