



THE RIGHT TO KNOW

New Approaches to HIV Testing and Counselling



1. KNOWING YOUR HIV STATUS – THE FIRST STEP TO ACCESSING CARE AND PREVENTING FURTHER INFECTION

People have a right to know their HIV status, and testing and counselling should be widely accessible through innovative, ethical and practical models of delivery. HIV testing and counselling are entry points to HIV-related care and prevention services, and provide opportunities for people to reduce their risk of acquiring or transmitting HIV. High priority should be given to scaling-up HIV testing and counselling to maximize the opportunities to reach those with HIV infection or at high risk.¹

The changing face of the HIV/AIDS epidemic has resulted in new opportunities, as well as new imperatives, to increase access to HIV testing and counselling and to knowledge of HIV status. Increased access to care and treatment, and decreased stigma and discrimination in many settings present important new opportunities associated with taking an HIV test. The fact that more and more of those infected with HIV need care and treatment based on knowledge of HIV status indicates new imperatives. HIV testing and counselling services must keep pace with the new opportunities if the increasing benefits of knowing your HIV status are to be accessed (see **Box One**).

New approaches to HIV testing and counselling must now be implemented in more settings, and on a much larger scale than has so far been the case. WHO is advocating that health-care workers should offer testing and counselling to all those who might benefit from knowing their HIV status, and then benefit from advances in the treatment and prevention of HIV infection and HIV-related diseases. As such benefits increase, there is an onus on national governments to provide good-quality testing and counselling services. The time has now come to implement HIV testing and counselling more widely using existing health-care settings, moving beyond the model of provision that relies entirely upon concerned individuals seeking out help for themselves to permit broader access for all. In this new approach, such services will become a routine part of health care, for example during attendance at antenatal clinics, or at diagnosis and treatment centres for tuberculosis and sexually transmitted infections (STIs).

These innovations cannot come quickly enough. In many parts of the world most severely affected by HIV/AIDS, fewer than one in ten people with HIV know that they are infected. This widespread ignorance of HIV status is the direct result of poor access to HIV testing, or serious problems with its delivery and uptake. In such settings, the lost opportunities for providing care and for strengthening prevention efforts are enormous. Many of the potential benefits for individuals and communities shown in **Box One** cannot be realized unless people are able to know for sure whether they are infected or not.

¹ *Global Health-Sector Strategy for HIV/AIDS 2003–2007. Providing a Framework for Partnership and Action.* Geneva, World Health Organization, 2003 (unpublished document HIV/2002.25).

BOX ONE

KNOWING THEIR HIV STATUS ENABLES

INDIVIDUALS TO:

- ▶ Initiate or maintain behaviours to prevent acquisition or further transmission of HIV
- ▶ Gain early access to HIV-specific care, treatment and support
- ▶ Access interventions to prevent transmission from mothers to their infants
- ▶ Better cope with HIV infection
- ▶ Plan for the future.

AND HELPS COMMUNITIES TO:

- ▶ Reduce the denial, stigma and discrimination that surround HIV/AIDS
- ▶ Mobilize support for appropriate responses.

2. NEW APPROACHES TO PROVIDING HIV TESTING AND COUNSELLING

HIV testing and counselling must now be implemented on a broader and radically larger scale in order to meet an increasing global demand for access to care and prevention services.

As treatment and care become more widely available it will be necessary to move beyond a single, rigid model of providing HIV testing and counselling and ensure that such services are available:

- ▶ for all those who want to know their HIV status
- ▶ wherever medically indicated in the context of clinical care
- ▶ as part of services for preventing HIV infection among mothers and their infants.

Although the offer of an HIV test may become standard practice under any of these circumstances, it should only be performed in accordance with the guiding principles outlined in **Box Two**.

HIV testing for those who want to know

The traditional model of voluntary testing and counselling which is being implemented in many places with excellent results requires significant commitments in terms of time, resources, infrastructure and trained staff. One-to-one counselling and the time required to provide it are possible disincentives for people who wish to be tested on a more routine and perhaps less conspicuous basis.

Additionally, young people may not have adequate access to HIV testing and counselling services. Innovative services should now be expanded to provide for them and to overcome the legal and cultural obstacles to testing and counselling they face. At the same time, in both high-prevalence and low-prevalence settings it is recommended that testing and counselling be offered as a priority service to all those considered to be at high risk of HIV infection, especially to vulnerable and marginalized populations such as injecting drug users, and men who have sex with men.

HIV testing and counselling in the context of clinical care

WHO recommends that HIV testing and counselling be offered whenever a patient shows signs or symptoms of HIV infection or AIDS, or wherever this will aid their clinical diagnosis and management. Under these conditions, the offer of HIV testing and counselling should be considered as the standard of care. However, routine HIV testing is not recommended for surgical patients in any setting unless HIV status has important implications for patient management. As with any other invasive test procedure, informed consent is required for an HIV test in the context of clinical care. Such informed consent should be obtained during the normal process of consultation between the health-care provider and the patient on the proposed course of treatment.

B O X T W O

WHAT ARE THE GUIDING PRINCIPLES OF EXPANDED

Testing and counselling must now be scaled up

Offering HIV testing and counselling should become standard practice wherever they are likely to enhance the health and well-being of the individual. The objective is to enable the greatest possible number of people to benefit from the ever-improving treatment, care and prevention options and realize their right to the highest attainable standard of health care.

HIV testing should be voluntary

Mandatory HIV testing is neither effective for public health purposes nor ethical, because it denies individuals choice, and violates principles such as the right to health, including the right to privacy and the ethical duties to obtain informed consent and maintain confidentiality.

Although the process of obtaining informed consent will vary according to different settings, all those offered the test should receive sufficient information and should be helped to reach an adequate understanding of what is involved. The three crucial elements in obtaining truly informed consent in HIV testing are:

- ▶ Providing pre-test information on the purpose of testing, and on the treatment and support available once the result is known
- ▶ Ensuring understanding
- ▶ Respecting the individual's autonomy.

Only when these elements are in place will individuals be able to make a fully informed decision on whether or not to be tested in light of their own circumstances and values. Once this is assured, the actual process of obtaining informed

Preventing HIV infection among mothers and their infants

In order to support the primary prevention of HIV infection among women of reproductive age, and the reduction of unintended pregnancies among HIV-positive women, HIV testing and counselling should be offered to women in free-standing clinics or in conjunction with other services (for example, family planning). In addition, where HIV infection is prevalent, HIV testing and counselling services should be routinely offered in antenatal care clinics as the standard of care. In this setting such services meet standards of best practice if at the very least they involve the provision of pre-test information in a group setting, followed by the offer of an HIV test as standard procedure. In so-called “opt-in” approaches, women have to request the test

specifically. In “opt-out” approaches they have to specifically decline the test if they do not want it to be performed. Both of these approaches are acceptable if women are individually informed that they have the right to refuse the test and are given the opportunity to do so.

3. EXPANDING ACCESS TO HIV TESTING AND COUNSELLING

The challenges involved in shifting the provision of HIV testing and counselling from a clinic-based approach to a more routine and widespread public-health model will be considerable, but the potential benefits are enormous.

It is estimated that by 2005 there will be up to 180 million people in need of testing and counselling annually. Enhanced quality of life and the potential financial savings which could result from better access to care, treatment and prevention will be many times greater than the original cost of expanding such services^{2,3}.

Improvements in quality of life and the associated savings will only be realized if efforts to expand HIV testing and counselling services are linked to care, treatment and support programmes. The lack of needed human, technical and financial capacity must be addressed. Furthermore, disincentives to HIV testing and counselling due to denial, stigma, discrimination, and the unequal status of women must be countered. Wherever possible, the use of rapid HIV tests should be an important component in the expansion of testing and counselling services. There is also an urgent need to increase the capacity of health care workers to deliver quality counselling, for example by developing cadres of professional counsellors, using lay counsellors, and improving the counselling ability of various health-care professionals such as clinical officers and nurses. In clinical settings, a team approach may be employed in which the health-care provider is the first-line counsellor with professional or lay counsellors (including those affiliated to nongovernmental organizations) providing more intense counselling. Pre-test information may be complemented and reinforced by using print and other media. With appropriate support, people living with HIV/

2 Chequer P et al. Access to antiretroviral treatment in Latin American countries and the Caribbean. *AIDS*, 2002, 16(Suppl 3): S50-S57.

3 Galvao J. Access to antiretroviral drugs in Brazil. *Lancet*, 2002, 360 (Issue 9348): 1862-1865.

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consent can be adapted to suit the different settings under which expanded HIV testing and counselling services will be implemented.

Post-test support and services are crucial

The result of HIV testing should always be offered to the person being tested. Along with the result, appropriate post-test information, counselling or referral should be offered according to the result. People who receive positive test results should receive counselling and referral to care, support and treatment.

Confidentiality must be protected

All medical records, whether or not they involve HIV-related information, should be managed in accordance with appropriate standards of confidentiality. Only health-care professionals with a direct role in the management of patients or clients should have access to such records, and only on a “need-to-know” basis^a.

While all of these principles are critical whenever HIV testing and counselling are considered, the ways these principles are applied will vary depending on the settings in which testing and counselling are implemented.

^a In rare circumstances, confidentiality can be breached where there is a clear indication that a third party may be harmed by the actions of the patient – ways of handling such circumstances are described in *Opening up the HIV/AIDS epidemic: Guidance on encouraging beneficial disclosure, ethical partner counselling & appropriate use of HIV case-reporting*. Geneva, UNAIDS/WHO, 2000 (UNAIDS/00.42E).

AIDS can themselves help to fill the human-capacity gap in almost all aspects of HIV testing and counselling.

Operational research is required into the various models of testing and counselling in order to determine their relative effectiveness, costs and social impacts. Testing and counselling should be made available in a broader range of public-health settings, including tuberculosis detection and treatment services, STI treatment services for sex workers and their clients, and health services for men who have sex with men. In this way, people presenting with other health concerns will be reached, and HIV testing and counselling services can be integrated into services for key populations currently unable to access the benefits that can result from knowing their HIV status. Finally, communities themselves should be helped to understand the purpose and potential benefits of testing and counselling, and hence be mobilized to support its widespread and routine availability.

4. WHAT IS WHO DOING ABOUT HIV TESTING AND COUNSELLING?

WHO is developing strategies for expanding access to HIV testing and counselling and for ensuring that they are performed in accordance with appropriate ethical and technical standards.

WHO has convened a series of international consultations on the approaches now needed for HIV testing and counselling, and has identified the priority tasks in expanding the provision of HIV testing and counselling services, including:

- ▶ advocating for expanded access to testing and counselling services, especially in the context of accelerating access to treatment, and efforts to prevent infection among mothers and their infants
- ▶ setting standards and providing guidance to support and improve the quality of testing and counselling in clinical and antenatal care settings
- ▶ providing technical support with key partners to countries, and at the regional and global levels
- ▶ strengthening partnerships in the implementation of testing and counselling, particularly within communities most affected by HIV/AIDS

- ▶ documenting currently effective models from which lessons can be learned and transferred.

Enormous numbers of people need to know their HIV status. WHO is therefore committed to working with governments and other partners to help bring about marked and rapid increases in access to HIV testing and counselling services across a much broader range of settings than is currently the case. In the near future, millions of people must be offered HIV testing and counselling under conditions that will benefit their health, enhance their lives, and lead to greater access to the care, support and treatment that they need.

This document is based on the report of the WHO consultation on increasing access to HIV testing and counselling, 19-21 November, 2002, held in Geneva, Switzerland. The report is in press.

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