

Increasing Access to HIV Testing and Counselling

Report of a WHO Consultation
19-21 November 2002
Geneva, Switzerland



World Health Organization

Acknowledgements

The contents of this report comprise the findings of a WHO Consultation on Increasing Access to HIV Testing and Counselling held in Geneva, Switzerland in November 2002. We thank all the participants (Annex 1), many of whom contributed to successive drafts of this document. We also thank many other colleagues who gave valuable input to the discussions forming the basis for this document.

Susan Timberlake prepared this report. The responsible WHO staff members were Scott McGill, Isabelle de Zoysa and David Miller.

WHO Library Cataloguing-in-Publication Data

WHO Consultation on Increasing Access to HIV Testing and Counselling (2002 : Geneva, Switzerland)

Increasing access to HIV testing and counselling : report of a WHO consultation, 19-21 November 2002, Geneva Switzerland.

1.HIV infection – diagnosis 2.HIV infection – psychology
3.Acquired immunodeficiency syndrome - prevention and control 4.Counseling 5.Mass screening 6.Health services accessibility 7.Delivery of health care. I.Title.

ISBN 92 4 159090 4 (NLM classification: WC 503.1)

All rights reserved. Publications of the World Health Organization can be obtained from Marketing and Dissemination, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland (tel: +41 22 791 2476; fax: +41 22 791 4857; email: bookorders@who.int). Requests for permission to reproduce or translate WHO publications – whether for sale or for noncommercial distribution – should be addressed to Publications, at the above address (fax: +41 22 791 4806; email: permissions@who.int).

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

The World Health Organization does not warrant that the information contained in this publication is complete and correct and shall not be liable for any damages incurred as a result of its use.

Printed in Switzerland

Contents

Executive summary	3
Introduction	7
Description of the consultation	8
The current context and its relevance to HIV testing and counselling .	9
Challenges to increasing access to HIV testing and counselling	12
Guiding principles	14
Models of service delivery	16
Diagnostic HIV testing and counselling in clinical care settings	16
Prevention of HIV infection in mothers and infants	17
HIV testing and counselling in preventing HIV infection	19
Supportive environments	21
Linking HIV testing and counselling to treatment, care and support	21
Community mobilization	21
Policy and legal framework	22
Country experiences	23
Conclusions and next steps	24
Annex 1. List of participants	25
Annex 2. Agenda	29

Executive summary

Knowing your HIV status – the first step to accessing care and preventing further infection

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 prevention of HIV infection and treatment of HIV-related diseases. As such benefits increase, there is an onus on national govern-

ments 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.

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 people's poor access to HIV testing, or to 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.

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.

Executive summary

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. Young people in particular 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 clinically indicated 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.

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.

Box Two – What are the guiding principles of expanded HIV testing and counselling?

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 must 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 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 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 is considered, the ways these principles are applied will vary depending on the settings in which testing and counselling is 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).

Executive summary

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.

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 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 non-governmental 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/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, 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 populations currently unable to access the benefits which 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.

Introduction

WHO is developing strategies to expand access to HIV testing and counselling services to increase knowledge of HIV status and to spread the benefits of such knowledge. For the individual, these benefits include enhanced ability: to reduce one's risk of acquiring, being further exposed to or transmitting HIV; to access HIV-specific care, treatment and support; to manage one's health; and to plan for the future. For communities, more widespread knowledge of HIV status and its link to HIV interventions can lead to better community mobilization against the epidemic and to less denial, stigma and discrimination.

The link between knowledge of HIV status and effective prevention, care and treatment has always been critical, but it has become even more so with the changing face of the epidemic. In the communities longest and hardest hit by the epidemic, ever-larger numbers of HIV-positive people are now becoming ill with AIDS-related disorders and need care and treatment. Nevertheless, only a small percentage of these people know their HIV status.

Knowledge of HIV infection is necessary to access many forms of HIV-related support, care and treatment. As drugs become more affordable and political commitment and financial resources in support of access rise, greater access to care and treatment, including antiretroviral therapy, is becoming much more of a real possibility. Programmes are in place to increase the access to antiretroviral drugs in general, and in particular, to prevent mother-to-child transmission. Further, where treatment, care and support have become more widely available, stigma and discrimination, which have always been disincentives to HIV testing, have reportedly decreased.

Given that the changing landscape of the HIV/AIDS epidemic has resulted in new opportunities as well as new imperatives to increase knowledge of HIV status, WHO held a consultation in December 2001 to begin to explore

approaches to delivering HIV testing and counselling services¹. At that consultation, participants endorsed the standard model of voluntary counselling and testing (VCT) as an effective way to address certain needs in certain settings. However, given the large and diverse populations that can benefit from HIV testing and counselling and the new opportunities to provide treatment in different settings, the participants also recognized the need for a greater variety of models in the provision of testing and counselling services that could be rapidly scaled up. Participants concluded that new models of HIV testing and counselling should retain their commitment to voluntariness and informed consent; should be adapted to different populations, service delivery settings; and should be capable of rapid expansion.

In November 2002, WHO convened a larger consultation to consider strategies to increase access to HIV testing and counselling. Those at the Consultation reconfirmed the commitment to voluntary HIV testing and counselling and explored new modalities by which to ensure informed consent as access to HIV testing and counselling expands in a variety of settings. In this context, the participants urged that HIV testing and counselling be offered as standard best practice in the provision of prevention, care and treatment services whenever testing and counselling can benefit the health and well-being of those affected by HIV/AIDS. This report summarizes the main conclusions reached at this Consultation.

¹ *Increasing access to knowledge of HIV status: conclusions of a WHO consultation, 3–4 December 2001* (http://www.who.int/entity/hiv/pub/vct/hiv_2002_09_en.pdf). Geneva, World Health Organization, 2002 (WHO/HIV/2002.09; accessed 24 April 2003).

Description of the consultation

The overall purpose was to consider ethical, innovative and pragmatic approaches to increase access to and uptake of HIV testing and counselling services and thereby to enhance efforts to promote HIV prevention, care and treatment. (Annexes 1 and 2).

The specific objectives of the consultation were to consider in more detail

- ▶ informed consent and guiding principles related to various models of HIV testing and counselling;
- ▶ strategies and models of service delivery that would increase knowledge of HIV status and help meet current targets and priorities in prevention and care; and
- ▶ the steps required for scaling up HIV testing and counselling programmes.

The list of participants and the meeting agenda are attached

HIV testing occurs in the following settings : (a) stand-alone or integrated voluntary testing and counselling services for people wishing to learn their HIV status; (b) testing in clinical care settings (primary care clinics, hospitals, offices of clinicians); (c) testing for preventing transmission from mothers to their infants; (d) testing in specialized clinics, such as those for family planning, antenatal care, sexually transmitted infections and substance use; (e) testing in other settings, such as the workplace, police stations, prisons and the armed services; and (f) testing as a precondition to access to such goods as employment, travel, migration or insurance. This Consultation primarily focused on testing that is voluntary, is conducted with the provision of information and/or counselling and occurs in the context of clinical care, programmes to prevent infection in mothers and infants and standard voluntary counselling and testing (VCT) services.

The current context and its relevance to HIV testing and counselling

Elements of the changing context of the HIV/AIDS epidemic compel a different and expanded approach to the provision of HIV testing and counselling. These involve changes in the perceptions and realities of the benefits and disincentives associated with knowing one's HIV status. Knowledge of HIV status has always had the potential for benefiting an individual's health and well-being and for helping to prevent the further transmission of HIV. Knowledge of HIV status has been especially beneficial when it has enabled people to access care, support and treatment, in the form of psychosocial support; home-based care; nutritional support; palliative care; treatment for opportunistic infections, tuberculosis and sexually transmitted infections; and antiretroviral therapy.

In many places, however, access to care, support and treatment has been very limited. Access to antiretroviral therapy has been, and still is, largely unavailable for most of the people needing it. Three million people needing antiretroviral therapy are envisaged to have access to it by the end of 2005. Further, in many communities, people who are HIV positive, or fear they are, face stigma and discrimination. Denial, lack of access to care and treatment as well as stigma and discrimination have acted, and continue to act in some places, as serious disincentives to people wanting to know, or to disclose, their HIV status.

Mandatory testing is counter-productive

In this context, HIV testing has had a problematic place in the response to the epidemic, especially in the early years of the epidemic. Some policy-makers have promoted mandatory testing for either the general population or for certain groups considered to be at "high risk". This has been promoted largely as a means of identifying people who might pose a risk of transmitting infection to other people. When carried out, such testing has often had a punitive outcome (such as discrimination, stigma, imprisonment and/or loss of employment) and no health benefit. From a public health viewpoint, there has been concern that mandatory testing tended to drive away the very people who needed HIV interventions.

Mandatory HIV testing has been rejected as being neither feasible nor affordable, as being ineffective in achieving public health objectives and as being an impermissible vio-

lation of human rights. For these reasons, the World Health Assembly, WHO, UNAIDS, the United Nations Commission on Human Rights and many other international and national groups have spoken out against mandatory testing². The participants agreed that mandatory HIV testing will not be helpful in meeting public health objectives.

Testing in clinical care

HIV testing has also been problematic in the context of clinical care. This is because, in many places, HIV testing has reportedly either not been conducted at all as part of clinical care or has been conducted without consent, confidentiality, counselling, the provision of results or any follow-up care to benefit health. Even in places where people with AIDS occupy more than 50% of hospital beds, almost none of these people have been diagnosed as HIV positive or told that they have AIDS. Although this phenomenon may result from fear that these patients will face discrimination or be denied health insurance, etc., if they are diagnosed as having AIDS, it also appears to be a form of medical denial that ultimately does not serve the best interests of these people or their families or communities. Few protocols have been developed to provide guidance about the appropriate use of HIV testing in clinical care settings.

Voluntary Counselling and Testing

Nevertheless, voluntary HIV counselling and testing (VCT) has functioned as an effective and ethical public health tool. In the standard model of VCT, the overall objective has been prevention, with an emphasis on confidentiality and voluntary individual decision-making, including protecting the individual's decision not to be tested and/or not to learn the result of the test. Counselling in VCT has involved dialogue between counsellor and client, emphasized safe behaviour, provided support for behavioural change and been neutral or even dissuasive in respect of the client's decision to be tested. Because it has been confidential and has been non-threatening with regard to testing, VCT has tended to attract those who might otherwise shy away from HIV intervention. From a public health perspective, VCT has therefore served to connect many people to paths related to HIV prevention and care.

² For a list of such statements, see: *HIV/AIDS and human rights: international guidelines* (<http://www.unaids.org/publications/documents/human/law/>)

The current context and its relevance to HIV testing and counselling

This model of VCT has been shown to be effective in increasing understanding of risks, providing a supportive environment in which to learn one's HIV status, achieving behavioural change for prevention and increasing access to support. When it has been widely implemented in a context of community mobilization, it has also helped to open up the epidemic; decrease denial, stigma and discrimination; increase opportunities for counselling for couples; and involve greater numbers in the response³.

However, VCT has not been implemented on a large scale in many low-income communities and countries, including those hardest hit by the epidemic. One reason is that the standard model of VCT is expensive and difficult to implement, as it requires substantial infrastructure, time and trained staff. Another reason is the fact that the uptake of VCT has been low where there are disincentives to learning of one's status.

Obstacles and opportunities in scaling up testing and counselling

Denial, stigma and discrimination as well as lack of access to treatment, care and support continue to exist in many countries and communities. Testing without consent, confidentiality or beneficial outcomes still remains a major problem in many places. Trying to address these realities is important in implementing any HIV testing and counselling programme or procedure. Nevertheless, important developments in the political, social and care contexts of the epidemic compel the implementation of different, innovative and expanded approaches to HIV testing and counselling while remaining committed to the principles of voluntariness, informed consent and confidentiality.

The United Nations General Assembly Special Session on HIV/AIDS held in 2001 and other important political initiatives provide evidence that, in the last few years, the international community, many governments and key elements in the private sector have overcome denial and are

demonstrating a new commitment to addressing the prevention and care challenges of the epidemic. There has also been recognition of the real extent of the resources needed to fight the epidemic, and new efforts have been made to mobilize these, such as the World Bank Multi-Country HIV/AIDS Program for the Africa Region and the Global Fund to Fight AIDS, Tuberculosis and Malaria. Further, political leadership, community involvement and multi-sectoral approaches have shown that stigma, denial and discrimination can be overcome and positive results can be reached in prevention and care, such as in Senegal, Thailand and Uganda.

New access to effective treatments

In addition to this new political and social context, access to treatment and care, which has always been an ethical and human rights imperative, has now become much more of a real possibility. The prices of critical treatments, including antiretroviral drugs, have dropped drastically, creating the opportunity for millions more to benefit from life-saving treatment and, in the case of infants of HIV-infected mothers, to benefit from preventing transmission from mother to child. Governments have shown much greater commitment to increasing access to treatment, care and support and, indeed, formalized this commitment at the United Nations General Assembly Special Session on HIV/AIDS⁴. They have also agreed to reduce by 20% the proportion of HIV infections in infants by the year 2005 by providing HIV testing and counselling services to the majority of pregnant women in affected countries⁵. At the XIV International AIDS Conference in Barcelona in July 2002, a global target of antiretroviral treatment for 3 million people by the end of 2005 was accepted as the immediate goal for increasing access to treatment.

Several national and international initiatives to increase access to treatment are currently under way, including the formation of the International HIV Treatment Access Coalition and various partnerships involving governments

³ *HIV voluntary counselling and testing: gateway to prevention and care* (<http://www.unaids.org/publications/documents/health/counselling/JC729-VCT-Gateway-CS-E.pdf>). Geneva, UNAIDS, 2002 (accessed 12 May 2003).

⁴ *Declaration of Commitment on HIV/AIDS*, United Nations General Assembly Special Session on HIV/AIDS, 25–27 June 2001 (<http://www.un.org/ga/aids/coverage/FinalDeclarationHIV/AIDS.html>). New York, United Nations, 2001, paragraphs 55–57 (accessed 24 April 2003).

⁵ *Declaration of Commitment on HIV/AIDS*, United Nations General Assembly Special Session on HIV/AIDS, 25–27 June 2001 (<http://www.un.org/ga/aids/coverage/FinalDeclarationHIV/AIDS.html>). New York, United Nations, 2001, paragraph 54 (accessed 24 April 2003).

and pharmaceutical companies and the companies and initiatives involved in the generic production of antiretroviral agents. Numerous programmes have been started and significant funding identified for preventing mother-to-child transmission of HIV and providing treatment and support to mothers and their infants, partners and families. The vital role of people living with HIV/AIDS in prevention and care has been increasingly recognized and made a reality.

Given this evidence of an international and national movement toward greater access to treatment and care, HIV testing and counselling has a critical role in this process. As knowledge of positive infection status is a prerequisite to the provision of antiretroviral drugs, including in preventing infection from mothers to their infants, HIV testing and counselling becomes a necessary and first step in realizing greater access to treatment. Even where treatment is not available, knowledge of HIV status, and hence HIV testing, can be critical in preventing HIV infection from being acquired and transmitted; can help to reduce stigma and discrimination; and can act as an essential diagnostic tool that leads to better management of a person's health.

Nevertheless, the vast majority of people in the world do not have access to HIV testing and counselling by which to learn of their HIV status and, with this knowledge, to access prevention, care and treatment services that are avai-

lable now or are likely to become available in the future. Given this reality, the participants confirmed the need :

- ▶ to increase knowledge of HIV status so as to decrease denial, stigma and discrimination and to increase beneficial prevention, care and treatment opportunities;
- ▶ to expand access to HIV testing and counselling so that the lack of such access does not become a barrier to increased uptake of treatment, care and support as provided for in the goals of the United Nations General Assembly Special Session on HIV/AIDS;
- ▶ to link efforts to increase access to HIV testing and counselling to efforts to expand access to prevention, treatment and care;
- ▶ to improve current practices in testing and counselling, which in many places are limited, unethical and do not lead to health benefits; and
- ▶ to describe and document innovative, pragmatic and ethical modalities of HIV testing and counselling in a variety of settings, the standards that should guide these modalities and strategies for expanding access to them.

WHO should provide support and guidance to governments

The provision of HIV testing and counselling can involve the following components, each of which has different ethical and/or programmatic implications :

- ▶ mobilizing the community around the acceptability and desirability of HIV testing and counselling;
- ▶ the client deciding to access services that offer HIV testing and counselling;
- ▶ providing information and/or counselling to the client on HIV testing and the implications and likely outcomes based on the result of the test;
- ▶ the client voluntarily giving informed consent to be tested or not tested;
- ▶ the client undertaking the HIV testing procedure;
- ▶ the results being provided to the client;
- ▶ client being provided post-test information, counselling and/or referral;
- ▶ the client taking up follow-up procedures, treatment or other forms of support.

Challenges to increasing access to HIV testing and counselling

Increasing access to HIV testing and counselling poses challenges. An enormous number of people might benefit from HIV testing and counselling. One estimate was that a global total of 180 million people would need HIV testing and counselling annually by 2005. This includes: up to 100 million in preventing mother-to-child transmission, 12 million in clinical care and 67 million in prevention⁶. Although these estimates could change if underlying assumptions are modified, such an exercise is necessary to begin to understand the resources that will be required to meet the goals of the United Nations General Assembly Special Session on HIV/AIDS. These figures are daunting, but they represent the potential number of those in need of testing and counselling and not necessarily the pool of people who would actually avail themselves of such services. Further, successes in other public health endeavours give hope that achieving something close to these goals is possible.

Another immense challenge discussed was the potential cost of HIV testing and counselling services. Assuming a modest cost of US\$ 10 per client for 180 million clients, this would result in a global annual cost of US\$ 1.80 billion⁷. Given this extremely high cost, urgent needs include being strategic, lowering the cost of counselling and testing through the use of different appropriate models while maintaining quality and setting priorities among efforts in terms of populations served and the objectives to be reached. Among other things, costs could be reduced by reducing the time spent in pre-test and post-test counselling. The costs would probably vary according to setting. For example, those needing testing and counselling in clinical care and preventing infection in mothers and infants might entail costs closer to US\$ 4 per client, whereas testing and counselling in traditional VCT, which involves intensive one-on-one pre- and post-test counselling, might cost closer to US\$ 10 per client.

Throughout the consultation, many concerns were raised about the lack of human, technical and financial capacity to increase access to HIV testing and counselling. In terms of human capacity, this included the need for: sufficient numbers of counsellors from various backgrounds; sufficient time for counselling appropriate to various settings; and sufficient numbers of phlebotomists and laboratory staff. Strategies mentioned to address these needs included greater use of people living with HIV/AIDS as both lay and professional counsellors, using community volunteers in counselling and educational processes and creating a new cadre of paid counsellors, thereby recognizing (non-nurse) counsellors as a professional category. Employment of such counsellors would be less expensive and allow greater potential for expansion. Appropriate eligibility criteria and appropriate curricula and training would be required for these counsellors. In terms of technical capacity, physicians, nurses and other health care providers need training in: the ethical principles of informed consent, confidentiality, ethical disclosure and partner counselling; storage and quality management of test kits; the use of test kits, including rapid tests; and record-keeping.

Another major challenge, the level of which differs according to local circumstances, involves the environment in which HIV testing and counselling are delivered. HIV testing and counselling programmes need to be tailored to the realities faced by potential clients, including: the prevalence of HIV infection; the actual availability of treatment and care; the existence of denial, discrimination and stigma; and barriers to testing and counselling posed by age, legality, socioeconomic status and gender. Among other things, these factors significantly affect the likelihood that a client will access services, agree to be tested, return to receive testing results and remain in the programme to receive the necessary follow-up. The lack of appropriate policy, legal and enforcement frameworks are important

⁶ From the presentation at the *Consultation Estimating the need for HIV testing and counselling* on 19 November 2002, prepared by Kevin O'Reilly and Abiola Johnson, WHO. Available on request from WHO.

⁷ From the presentation at the *Consultation What is the cost of HIV counseling and testing?* prepared by Michael Sweat, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD, USA. Available on request from WHO.

obstacles to ensuring the ethical and effective implementation of HIV testing and counselling. Women face obstacles in many societies in which their unequal status prevents them from being able to exercise real autonomy throughout the process of testing, counselling and follow-up. There are legal barriers to consent for minors and barriers caused by the criminalization of sex work and drug use.

Models of implementation should be tailored to address these elements. HIV testing and counselling should always be implemented in a manner sensitive to the community context, especially such factors as denial of or lack of access to services; coercion; lack of understanding, consent and confidentiality; and punitive or negative outcomes around testing. Every effort should be made to ensure that testing and counselling is voluntary, ethical and conducted in a supportive environment, results in beneficial outcomes and is conducted in a legal context enabling redress by the individuals concerned when ethical principles have been unjustifiably violated (as discussed in detail below).

These challenges should be incorporated in finding new and creative ways to overcome the challenges of scaling up and ensuring wider access to testing and counselling rather than continuing to inhibit the HIV testing and counselling process itself. Such an approach is especially indicated, given the positive changes in the HIV prevention and care context noted above and the crucial importance of HIV testing and counselling to prevention, treatment and care at this stage of the epidemic.

Guiding principles

The participants discussed and confirmed the relevance of the principles that should guide HIV testing and counselling procedures and programmes. These include principles that underscore the need to increase access to HIV testing and counselling – the right to the highest attainable standard of health care (the right to health); and other rights that support the right to health, such as the rights to non-discrimination, education, information and participation and the right to enjoy the benefits of scientific progress and its applications. They also include the principles that protect the individuals being tested from possible harm – the right to privacy and the ethical duties to obtain informed consent and maintain confidentiality⁸.

The right to health obligates governments to take legislative, budgetary and administrative steps towards the progressive realization of this right. The right to health includes the right to knowledge about one's health status – in this case, knowledge of one's HIV status through HIV testing and counselling. The right to health also includes the right to comprehensive care, treatment and support for health conditions, including for HIV/AIDS, and the medicines necessary to treat them. Since HIV testing is an essential first step to accessing such care, treatment and support, greater access to HIV testing should form a part of governments' obligations to realize progressively the right to health⁹. The rights to education, information and non-discrimination also support the individual's right to an HIV test where requested and/or

indicated for health care purposes and to treatment or follow-up as necessary and possible, depending on the result of the test.

The ethical principles of **informed consent and confidentiality** are important in the context of HIV testing and counselling. These principles protect individuals from unwanted violation of their person and/or unwanted disclosure of private information, including information about their health status. They are based on the underlying notion of autonomy – that an individual has the right and ability to make decisions on his or her person and private information, as opposed to a paternalistic approach in which the physician has the right and duty to make such decisions on behalf of the patient¹⁰. The right to privacy and the principles of informed consent and confidentiality can be limited in certain circumstances for the sake of avoiding harm to others¹¹.

Given that the context has changed towards the increased availability of care and treatment and a decrease in denial, stigma and discrimination, the balance has shifted in favour of voluntary HIV testing becoming a standard and necessary part of diagnostics, health care and health enhancement. Such a shift will better enable the greatest possible number of people to realize their right to the highest attainable standard of health care. As the offer of HIV testing and counselling becomes standard practice in the circumstances described below, informed consent and confidentiality should remain protected.

⁸ These principles can be found in international human rights instruments, such as the Universal Declaration of Human Rights; the International Covenant on Economic, Social and Cultural Rights; the International Covenant on Civil and Political Rights; the United Nations Convention on the Rights of the Child; the Convention on the Elimination of All Forms of Discrimination against Women; as well as in ethical principles that guide health care workers in the provision of health care. For more on their relationship to HIV/AIDS, see *HIV/AIDS and human rights: international guidelines* (<http://www.unaids.org/publications/documents/human/law/JC520-HumanRights-E.pdf>). Geneva, UNAIDS, 1999 (accessed 24 April 2003).

⁹ *United Nations entrenches human rights principles in AIDS response* (http://www.unaids.org/whatsnew/press/eng/pressarco2/Humanrights_100902.html). Geneva, UNAIDS and the Office of the High Commissioner on Human Rights, 10 September 2002 (accessed 24 April 2003). This describes the result of an international expert consultation on HIV/AIDS and human rights held in Geneva on 25–26 July 2002 that updated Guideline 6 on “Access to prevention, treatment care and support” of the International Guidelines on HIV/AIDS and Human Rights. The Consultation, among other things, emphasized how access to treatment is part of the right to health and that governments have a positive obligation to take measures to increase such access.

¹⁰ Based on research in Europe and Asia, the concept of autonomy in health care does not appear to be a wholly “Western” notion and is gaining ground across regions. See the presentation at the Consultation *Ethical issues in VCT* and the background paper *Informed consent and HIV testing* prepared by Reidar Lie, University of Bergen, Norway. Available on request from WHO.

¹¹ For more on limitations on these rights and principles, see: *HIV/AIDS and human rights: international guidelines* (<http://www.unaids.org/publications/documents/human/law/JC520-HumanRights-E.pdf>). Geneva, UNAIDS, 1999 (accessed 24 April 2003). See also: UNAIDS and WHO. *Opening up the HIV/AIDS epidemic* (<http://www.unaids.org/publications/documents/epidemiology/surveillance/JC485-Opening-E.htm>). Geneva, UNAIDS, 2000 (UNAIDS/00.42E; accessed 24 April 2003).

The process of obtaining *informed consent* should involve sufficient information, understanding and autonomy so that a person can decide to be tested or not tested for HIV, based on his or her circumstances and values. However, there are many valid models for ensuring that these elements of informed consent are satisfied. In this regard, different types of service delivery of testing and counselling are emerging in response to a variety of needs and possibilities of treatment. This is a positive and necessary development and overcomes any presumption that HIV testing and counselling can be provided in one way only. In this context, the means of implementing informed consent can also vary and should be adapted to the client group benefited, the outcomes sought and different settings of service delivery. The implementation of informed consent varies in the context of other medical tests that are conducted in various settings for the diagnosis and treatment of other conditions or diseases.

The standard model of VCT has often been held up as the gold standard of voluntariness in HIV testing. In the context of VCT, the client has usually chosen to avail him or herself of the service, is aware that HIV testing will be offered and, in fact, often approaches the service because she or he desires to be tested for HIV. This is in contrast to other settings, such as clinical care or antenatal care, where a person most likely takes up the service for reasons other than the desire to know his or her HIV status. Further, in VCT, the client is given one-on-one pre-test counselling about risk reduction and about consideration of an HIV test: that is, the potential benefits and drawbacks of a test. The client then consents to the test orally or in writing.

Approaches to informed consent that involve less individual and one-on-one attention and discussion can be acceptable as long as they ensure sufficient information, understanding and free choice. Such models might involve providing necessary information to a group or to individuals, coupled with some sort of assurance that the individual actually consents with understanding. The content of the information as well as the time spent with an individual to obtain informed consent might vary according to the service and community context. For instance, where stigma and discrimination are prevalent and women have low status, more time would likely be spent to ensure that a woman understands the HIV test and its consequences and voluntarily chooses to be tested. In other circumstances, less time might be sufficient. In the clinical care setting, informed consent would be obtained within the normal process of consultation between a health care provider and a patient, as discussed below.

The participants discussed the principle of *confidentiality* that should be applied to HIV testing and counselling. In many places, the confidentiality of information management generally needs to be improved across the board in these settings. It was hoped that developing protocols and better capacity to protect confidentiality in the context of HIV testing and counselling might improve practice in areas not related to HIV. Any HIV-related information should be kept confidential and disclosed only with the client's consent. If maintaining confidentiality might pose harm to others, care should be taken to follow relevant law or ethical practice in the particular locale.

All medical records, whether or not they involve HIV-related information, should be treated with the same standards of confidentiality. Only health care providers and professionals with a direct role in managing the patient or client should have access to such records on a need-to-know basis. Professional exchange of information pertaining to patients should be encouraged within the boundaries of medical ethics. Sanctions should be developed and applied when confidentiality is breached. The code of confidentiality for HIV testing and counselling in the clinical setting needs to be widely understood and strengthened.

Models of service delivery

The objective is to offer the right test to the right person at the right time. With this objective in mind, the participants examined different service delivery models pertaining to different objectives, client groups, institutions and environments. Service delivery of HIV testing and counselling and accompanying models of informed consent would necessarily look different according to the opportunities and challenges presented by each of these settings. In addition, many different models of HIV testing and counselling are currently being implemented, but few of these have been well documented or evaluated.

For all models of implementation of HIV testing and counselling: (a) pre-test information should indicate the nature of follow-up, treatment and support that would be available after the test depending on the result; (b) informed consent should be obtained; (c) appropriate confidentiality should be maintained; (d) the result of the test should be offered to the client; and (e) appropriate information, counselling or referral should be provided, as indicated by the test result.

Depending on the result, some sort of post-test follow-up should occur. For those who test negative, it may involve counselling or providing information on prevention. For all those who test positive, post-test counselling should be offered, as concerns need to be addressed such as the psychosocial impact of the positive result, the impact on the family and on employment and other issues or fears. Where appropriate, part of the role of counsellors is to encourage HIV-positive clients to disclose to prevent onward transmission, to get support or to help others who might be infected. Such disclosure should be carried out with the consent of the client if possible. Counsellors can help in identifying to whom clients should disclose and facilitate disclosure where the client is unable to disclose. A number of difficult issues concerning disclosure were noted, such as risks to others not related to the behaviour of the client (home care and funeral rites), country-specific legal obligations and the need to protect women from the potential violence and abandonment brought on by disclosure¹².

Optimum support necessary for any setting that offers HIV testing and counselling includes adequate space and privacy; trained and supported staff; programme management and

supervision; systems to manage information and confidentiality, assure quality, manage health care supplies and link clients to services; and data about the community served. Staff need protection from burnout and clear protocols for obtaining consent, keeping records and maintaining confidentiality.

Rapid tests increase the capacity to test and to provide results and should be a component of scaling up testing and counselling services. However, counselling in the context of rapid testing should be tailored to address any issues arising from the quick turnaround of results.

With these common elements and current public health imperatives in mind, the participants focused on the delivery of HIV testing and counselling in the context of three settings: (a) clinical care for those living with HIV and AIDS; (b) preventing HIV infection among mothers and infants; and (c) HIV prevention programmes aimed at the general public as well as at particular groups.

Diagnostic HIV testing and counselling in clinical care settings

Even though millions have already grown ill and died from AIDS and millions more are infected and ill, current practices regarding HIV testing and counselling in clinical care settings are poorly described, standards and protocols are few, counselling is often inadequate and lack of confidentiality and inappropriate disclosure are common. This situation urgently needs to be improved given the ever-increasing numbers who should benefit from diagnosis, treatment and care.

The participants felt that it is time to shift away from the perceived hopelessness about what can be offered after an HIV test. Even in settings where treatment is not yet available, knowledge of HIV status can open the way to benefits in terms of diagnosis, health management, social support and future planning. Communities should become involved in and support diagnostic HIV testing, and means should be found to address the potential negative effects of HIV testing. For diagnostic HIV testing to be done under the appropriate conditions outlined below, clinicians, health care providers and health care students must receive better training and support.

¹² For more on disclosure, including difficult issues related to a client's refusal to disclose, see: UNAIDS and WHO. *Opening up the HIV/AIDS epidemic* (<http://www.unaids.org/publications/documents/epidemiology/surveillance/JC485-Opening-E.htm>). Geneva, UNAIDS, 2000 (UNAIDS/00.42E; accessed 24 April 2003).

HIV testing and counselling should be offered as standard practice in the clinical care context when: (a) the patient has clinical symptoms suggesting HIV infection or AIDS; and (b) an HIV test is necessary to benefit the patient in terms of diagnosis and improving and managing health care. In such situations, HIV testing should always be linked with informed consent and post-test counselling and should be considered the best practice or the standard of care.

Everyone with tuberculosis should be offered an HIV test. HIV testing is not recommended as a routine for surgical patients in any setting, however, although some clinical presentations of surgical patients could suggest the need for HIV testing. Universal precautions should be taken, post-exposure prophylaxis available and health care providers supported as standard practice in surgical settings.

Informed consent is required for an HIV test in clinical care settings, as with any other clinically indicated invasive test. In the clinical care setting, the objectives are for the health care provider to diagnose the condition and offer treatment and for the patient to understand his or her condition and accept or reject the treatment offered. In such a context, informed consent for an HIV test should be obtained in the normal process of the consultation between a health care provider and a patient. This would likely entail a health care provider recommending to the patient a particular course of action, based on clinical assessment, including the clinical indications for an HIV test and brief assessment of the patient's readiness for HIV testing. If the patient agrees to the recommended course of action, consent can be considered to have been obtained. If the patient declines to go forward with the course of treatment and/or the HIV test, that decision would be respected.

Post-test counselling is necessary for everyone who tests positive for HIV in a clinical care setting. As health care providers in clinical care settings are often constrained in their ability to counsel, both in terms of time and capacity, the health care provider could act as a first-line counsellor informing the patient of the test result and its implications for health care. This includes discussing available interventions and then referring the patient to others for more in-depth counselling and ongoing support.

Follow-up counselling can be carried out by other health care professionals (such as clinical officers or nurses) or by lay counsellors, including people living with HIV/AIDS

who are trained in counselling. There are various models in which lay counsellors, nongovernmental organizations and people living with AIDS might provide counselling in the clinical and/or hospital setting. When possible, a team approach to testing and counselling should be developed within the clinical setting. Issues of power and authority arising in a health care hierarchy that might hinder a team approach might need to be addressed. With appropriate support, people living with HIV/AIDS could help fill the human capacity gap and be engaged in almost all aspects of HIV testing and counselling.

The primary health care level offers the greatest opportunity to improve and scale up the provision of HIV testing and counselling, where appropriate, in the clinical care setting, including in general health clinics and those offering predominantly curative services, such as for tuberculosis. Clinics for treatment of sexually transmitted infections also provide an important vehicle for scaling up testing and counselling access. However, much work should also be done to improve access to and the conditions of HIV testing and counselling in secondary- and tertiary-level hospitals as well as in private and traditional medical settings. In generalized epidemics, clinical care settings should be included in the range of settings for scaling up VCT, making VCT available in clinical settings to take advantage of patients' presence in the health setting. Operational research is needed into various models of testing and counselling in clinical care settings to determine the efficacy, costs and social impact of different models. Current WHO procedures should be reviewed with a view to increasing access to HIV testing.

Prevention of HIV infection in mothers and infants

HIV testing and counselling should be an essential aspect of the four components of the strategy to prevent HIV infection in mothers and infants. These are: (a) primary prevention of HIV among women of reproductive age; (b) reducing unintended pregnancies among women living with HIV; (c) reducing transmission from an HIV-positive mother to her child; and (d) providing care, treatment and support for mothers and their infants, partners and families¹³. In each of these components, HIV testing and counselling would take different forms depending on the context and the objectives.

¹³ *Strategic approaches to the prevention of HIV infection in infants: report of a WHO meeting, Morges, Switzerland, 20-22 March 2002*. WHO, 2003

Models of service delivery

For the first two components of preventing mother-to-child transmission (primary prevention among women of reproductive age and reducing unintended pregnancies among HIV-positive women), HIV testing and counselling might take the form of the standard VCT model available in free-standing clinics or VCT integrated into other services (including family planning services in high-prevalence areas) and other locales frequented by women of reproductive age. However, for reducing transmission from an HIV-positive mother to her infant, HIV testing and counselling services should be integrated into antenatal care clinics and be offered as standard practice in high-prevalence settings in the context of the services provided there. Informed consent to testing should always be obtained. Different models might be used to implement informed consent, as discussed below.

Some antenatal clinics provide pre-test information in standardized formats to groups of clients, such as in the form of an information session or video offered in the waiting room. Such a practice reduces costs and might increase the numbers of people exposed to HIV information on prevention and care. For most clients, such a practice is adequate to inform them of the critical issues on which they must make a decision to be tested or not tested, but the efficacy of this approach still needs to be studied. Nevertheless, if individuals cannot benefit from these sessions for such reasons as impaired vision or hearing or language barriers, special efforts have to be made to ensure information and understanding.

Several models are currently being used in antenatal care clinics involving an opt-in or opt-out approach. In the opt-in approach, the client is provided with information, including the offer of an HIV test. To undergo that test, she must specifically ask for it, thereby consenting to the test. In the opt-out approach, clients are offered an HIV test routinely as part of standard package. They are also told that they have the right to refuse the test, but they might not be explicitly asked whether they wish to be tested or not. Information, including that about an HIV test, may be provided in a group setting or in a one-on-one session. The burden is then on the client to refuse an HIV test (opt out) if she wishes to avoid it. If the client does not refuse the test, she is deemed to have consented to it. Another term that has been used to describe this sort of approach is the informed right of refusal. This approach may have the benefit of normalizing an HIV test and has been shown to significantly increase the uptake of testing¹⁴.

Some participants felt that the opt-out approach, in which the woman is offered HIV testing and counselling and has the option of declining to participate in this, was sufficient to protect informed consent. Others felt that informed consent was only ensured in the opt-out approach if the client was explicitly asked if she wanted to refuse the test.

Post-test counselling should be available to everyone tested in the context of preventing HIV infection in mothers and infants. For a negative result, such counselling could be brief, focusing on prevention objectives. For a positive result, all women should be offered high-quality counselling that would necessarily be more comprehensive. Apart from psychosocial support, it would include options for family planning and/or preventing transmission from mother to child, and counselling for couples or partners. Again, health care providers could perform first-line counselling, with more intensive post-test counselling being available from other staff, including either professional or other types of counsellors located at companion service sites (including community-based NGOs/CBOs).

Confidentiality should be appropriately maintained. Given the low status of women in many societies, care should be taken to ensure that the woman who was tested receives the results, chooses to whom she will disclose and receives appropriate support to disclose to partners and family members, including follow-up support in case of negative reactions.

Difficult issues pertaining to HIV testing and counselling arise when women present at the time of labour and delivery. This is a common problem, since in many places, a high percentage of women of unknown HIV status come in only for labour and delivery. In most cases, informed consent for HIV testing can be obtained in early labour or when women are being counselled about the need for caesarean section deliveries where these are indicated and when no seriously adverse factors are present, although this is not optimal. However, difficulties might arise in obtaining informed consent from women who are in advanced labour and/or are experiencing pain or adverse conditions. There are three options for this dilemma.

One option is to go ahead and try to obtain the best informed consent possible in the circumstances. This might mean obtaining less than optimal informed consent, but it would allow interventions to be targeted to those needing them, based on the result. This approach broadly follows

¹⁴ Basset M. Ensuring a public health impact of programs to reduce HIV transmission from mothers to infants: the place of voluntary counselling and testing. *American Journal of Public Health*, 2000, 92:347–351.

the practice in Brazil, whereby consent is obtained orally from women in such circumstances and that process is recorded in the chart, in contrast to written consent being obtained when there are no conditions of duress or difficult circumstances.

A second option would apply to areas of high HIV prevalence and would involve providing antiretroviral prophylaxis (without testing) to all women about to deliver, to be followed at an appropriate time by the offer of testing and counselling. The disadvantages of this approach are two-fold¹⁵: (a) it could expose HIV-negative women and their children unnecessarily to antiretroviral drugs, and (b) it leads to the inability to counsel the mother on infant feeding and family planning. Given the 72-hour window for provision of nevirapine to infants, a third option would involve providing nevirapine to the infant if the mother consents, whether or not she has had an HIV test. This option has similar disadvantages to the second one. Testing cord blood is not an option, as this is functionally the same as testing women without their consent.

The participants did not reach a conclusion regarding this difficult area. They suggested that the experience of countries and communities dealing with these issues be documented and that research be conducted into consent procedures in other situations of duress. Much greater efforts (mainly through community mobilization) should be made to get women to attend antenatal clinics before delivery, and every effort should be made to offer a test prior to labour.

Preventing infection in mothers and infants generally requires that women and their partners be prepared better and that the community be better mobilized. Greater efforts should be made within communities and among populations of women (including adolescent girls, who are being infected at a high rate) to ensure that they are aware of the link between pregnancy, breastfeeding and HIV transmission; are aware of the potential interventions to prevent mother-to-child transmission; understand the benefits of knowing their HIV status and hence of HIV testing and counselling; and find community and family support to access HIV testing and counselling and to follow through with necessary interventions. Male partners need to be involved as early as possible. The provision of treatment, care and support to women, their infants, their partners and families is a key component of a holistic, ethical and effective approach to preventing HIV infection in infants.

Community mobilization to achieve uptake of HIV testing and counselling as well as follow-through by women is important in preventing HIV infection in women and their infants. Greater efforts should be made to get communities more involved in these issues and to encourage them to accept HIV testing and counselling, to overcome barriers of stigma, discrimination and marginalization and to assist in increasing the positive involvement of women's partners in testing and counselling. Community mobilization might entail such strategies as implementing mass media and social marketing campaigns directed at women and their partners; using existing women's groups and young people's groups; using mass media and sports role models; implementing legal protection for women and young people accessing testing; reaching out to women and young people for testing and counselling; and encouraging testing and counselling for couples entering into new relationships.

Rapid testing should be a part of scaling up HIV testing and counselling in family planning and antenatal clinics, especially in resource-constrained settings. However, although rapid tests can increase the provision of results, counselling and social support should be tailored to deal with the issues raised by the short time frame the client has to prepare for the result. Women may be no more likely to take up interventions after a rapid test than after a regular test, unless they receive adequate support in doing so.

HIV testing and counselling in preventing HIV infection

In the context of HIV testing and counselling for preventing HIV infection, the VCT model was developed in the mid-1980s as the standard of care for individuals seeking to know their infection status. This model places as much, if not more, emphasis on counselling as on testing. Counselling in this model is usually one-to-one, is client-centred and focuses on providing HIV-related information, helping clients to develop a risk reduction plan and exploring whether the client wishes to be tested. The sequence followed is: pre-test counselling, HIV testing (if voluntarily chosen) and post-test counselling.

For those who test negative, post-test counselling might include further risk-reduction counselling and support. For those who test positive, post-test counselling might include psychosocial support and referral to necessary medical

¹⁵ *Prevention of mother-to-child transmission of HIV: use of nevirapine among women of unknown status: report of a technical consultation, Geneva, 5-6 December 2001* (<http://whqlibdoc.who.int/hq/20029241562129.pdf>). Geneva, World Health Organization, 2002 (accessed 12 May 2003).

Models of service delivery

services and social support services. Post-test services might also include support and crisis management, provision of condoms, partner notification and/or testing, and referral to sexually transmitted infection services¹⁶.

Informed consent is usually not problematic in the standard VCT model of HIV testing and counselling. The client initiates the use of the services and participates in pre-test counselling, which involves a discussion about the choice to be tested. However, there have been cases in which those participating in VCT have been pressured to do so, such as women or adolescent girls pressured by partners or employees pressured by employers. In some jurisdictions, minors cannot give consent to be tested and are thus legally barred from accessing VCT on their own. Those under the age of consent need to overcome legal barriers to the uptake of VCT, and the participants asked WHO to provide guidance on this issue.

VCT in many places has fulfilled a vital need, has helped to mobilize communities around HIV/AIDS and has reduced denial and stigma surrounding HIV/AIDS. Where it has functioned well, it has usually benefited from a supportive policy and legal environment and community mobilization to increase uptake. However, some problems are associated with the standard VCT model of HIV testing and counselling.

This model requires a great deal of time and infrastructure and a well-supported staff of trained counsellors. This makes it costly, slow and difficult to scale up quickly where the demand for HIV testing and counselling is high or growing. Further, many participants believed that strict adherence to in-depth pre-test counselling and an emphasis on secrecy (as opposed to appropriate confidentiality) may make this model too intense and complicated for some who wish to undergo an HIV test on a more routine basis.

Concern was also expressed that the efficacy and cost-effectiveness of the different elements of this model of VCT have not been fully established. For instance, in some settings and with some groups, counselling alone may be sufficient to change behaviour, such as for young people or for those to whom providing testing services is difficult, such as truck drivers. For other settings or groups, one-on-one counselling may be too intensive and costly

compared with some sort of group, structural or environmental process that may lead to behavioural change. Operational research is needed to explore a variety of models for delivering VCT for prevention purposes.

VCT services are not necessarily reaching those who need them, such as young people or vulnerable groups. Nor are such VCT services sufficiently linked to care services, especially for these groups. In some places, special approaches are necessary to improve access to VCT and to overcome legal, social and cultural barriers experienced by young people, women and others, such as sex workers, mobile populations, migrants, injecting drug users, prisoners and rural populations. Successful approaches have taken the form of outreach, mobile clinics, youth-specific clinics, integration of VCT into family planning or other service packages, such as VCT along with harm-reduction programmes for drug users. Links with other vital services can be the incentive by which to involve some hard-to-reach groups in a more holistic service package.

The participants discussed where and for which groups VCT or some form of testing and counselling for prevention might be recommended as a priority in resource-constrained settings. Priorities would necessarily be different in generalized epidemics, in contrast to concentrated or low-prevalence ones. In both high- and low-prevalence areas, VCT is recommended to be provided on a priority basis to the vulnerable populations described above, and to those in uninfected services and couples with HIV-discordant serostatus.

HIV testing should be routinely offered in sexually transmitted infection clinics to people diagnosed with sexually transmitted infections, since they have a high risk of acquiring or transmitting HIV and have engaged in unprotected sex.

¹⁶ *Tools for evaluating HIV voluntary counselling and testing* (<http://www.unaids.org/publications/documents/health/counselling/Tools.pdf>). Geneva, UNAIDS, 2000 (accessed 12 May 2003).

Supportive environments

As discussed above, the widespread use of HIV testing and counselling has been largely avoided in the past, as individuals or communities decided that the potential benefits of knowing HIV status did not outweigh the potential harms, such as stigma and discrimination. However, some communities, determined to face the epidemic openly and strongly, have been able to encourage more widespread knowledge of HIV status by maximizing the benefits that could be made available to those who know their status and providing encouragement and social support to undergo testing and counselling. In these communities, a supportive environment, more widespread knowledge of status and providing care and support at whatever level available have turned the tide on denial, stigma and discrimination. Now, when knowing HIV status may result in even greater benefits, communities, governments, donors, nongovernmental organizations and others should more aggressively make the link between HIV testing and counselling and health care, psychological and social support and treatment.

Given the serious consequences of a positive HIV test result, those considering being tested for HIV should always be supported. Further, where stigma, discrimination and lack of care and treatment still exist, much greater efforts have to be undertaken to create a supportive environment. Such an environment is essential to encourage those who need or want HIV testing and counselling to be willing and able to take it up. The three main elements of a supportive environment that would help to attract clients to health care or VCT services, support them to consent to a test and receive the result and enable them to follow through with the relevant interventions that would enhance their health and their lives are: strong links to treatment, care and support; community mobilization; and an appropriate policy and legal framework.

Linking HIV testing and counselling to treatment, care and support

HIV testing and counselling should only be conducted to enhance the health and well-being of the client. In this regard, it should always be linked to the provision of care and support, and where possible, treatment. Not only is this linkage ethical, it can also create dynamics that galvanize prevention and care efforts and greatly support their effectiveness.

Knowledge of HIV status has always had the potential to increase the ability of an individual and his or her health care provider to enhance health and well-being.

Unfortunately, millions of people have missed this opportunity in the course of the epidemic, as they have grown ill and died without any knowledge of their status. Even in resource-constrained settings where care and treatment are very limited, every effort should be made to link knowledge of status with available benefits. These might include: prevention of onward transmission to partners; better diet and nutrition; initiatives for positive living; home-based care; access to therapy for opportunistic infections, tuberculosis and sexually transmitted infections; palliative care; planning for the future (such as preparing wills and memory books); and post-test social support, such as that found in post-test clubs and other community groups.

There are important new opportunities to provide treatment to millions who need it. From the outset, efforts to increase access to HIV testing and counselling should be linked to the growing number of initiatives and programmes designed to increase access to antiretroviral therapy, management of tuberculosis, treatment for sexually transmitted infections and interventions to prevent transmission to women and children. Since knowledge of HIV status is a prerequisite to antiretroviral treatment and to the prevention of mother to child transmission, HIV testing and counselling forms an essential component of these initiatives and programmes.

Community mobilization

Community mobilization is critical to the success of increasing access to and uptake of HIV testing and counselling. It can be used to overcome the barriers of ignorance, denial, stigma and discrimination and to encourage people to utilize HIV testing and counselling services. Awareness of HIV/AIDS, which has largely been achieved, is not the same as understanding it and being motivated to do something about it. Community mobilization can be the force that gets people to act on their knowledge. There are powerful examples of communities supporting their members to enter and follow through with HIV testing and counselling services. This has occurred in communities defined by geography and in those defined by membership in a particular group, such as young people, women, sex workers, truck drivers and migrants. In fact, peer support is often the trigger for individuals to take up testing and counselling.

Community mobilization efforts that have been successful involve such elements as: political leadership; community-based media and social marketing campaigns; community discussion forums; using community role models, including people living with HIV/AIDS; integrating HIV testing

Supportive environments

and counselling into existing community services or into the activities of existing community groups (men, women and young people); community campaigns and social marketing against stigma and discrimination; training community health care and other service providers in nondiscrimination and ethics; and community faith-based initiatives.

Despite all the recognition and rhetoric concerning the increased involvement of people living with HIV/AIDS, they continue to be a tremendously underutilized resource. Involving people living with HIV/AIDS is not tokenism but is instead essential to achieving a holistic understanding of and response to the epidemic and is also practical and effective. With appropriate support, people living with HIV/AIDS can be engaged in almost all aspects of HIV testing and counselling: in designing, managing and administering programmes; as professional and lay counsellors; as people who help to provide psychosocial support; as links to other services and resources; and as people who help to mobilize the community through advocacy and activism around HIV testing and counselling.

Policy and legal framework

Appropriate legal and policy frameworks are important in combating discrimination based on HIV status. Many countries need legislation that recognizes discrimination based on health status, including HIV/AIDS, and provides legal sanctions for it¹⁷⁻¹⁸. Such legislation should cover both the public and private sectors. In many places, the legal system is weak and people do not have access to the courts. However, even in such places, much can be accomplished if there is legal support for those aggrieved and a few key court cases on HIV-related discrimination are brought to trial and won.

Policy and practices that encourage non-discriminatory behaviour are important. Policies against HIV-related discrimination and favouring support should be implemented

in all places that provide government services, including uniformed services and social services, such as public health, housing and public assistance. Much can and should be done in the private sector. The workplace remains a key area for policies that protect workers against discrimination and help to provide them access to prevention and care services, including HIV testing and counselling. Other areas should be made more supportive of HIV testing and counselling. One example is the counterproductive policies of some insurance companies to deny benefits once HIV/AIDS is diagnosed. Not only does such a policy result in a tragic denial of support, but it also makes clinicians less likely to diagnose HIV, document it in clinical records and provide appropriate follow-up.

In many places, health care workers continue to discriminate against those living with HIV/AIDS. They do this partly because they lack sufficient training about HIV and AIDS and partly because of a valid fear of acquiring HIV infection through their work. If the offer of HIV testing and counselling is to become standard practice where clinically indicated, health care workers should be empowered to provide health care in an ethical and nondiscriminatory manner. Such empowerment would involve: (a) working in the context of an appropriate policy framework; (b) training in the management of HIV and the use of universal precautions; (c) providing the means by which to implement universal precautions and post-exposure prophylaxis, where antiretroviral drugs are available; and (d) training in the principles of informed consent and confidentiality, nondiscrimination, acceptance and compassion.

¹⁷ For more on appropriate legislation related to HIV/AIDS, see: *HIV/AIDS and human rights: international guidelines* (<http://www.unaids.org/publications/documents/human/law/JC520-HumanRights-E.pdf>). Geneva, UNAIDS, 1999 (accessed 24 April 2003).

¹⁸ *Handbook for legislators on HIV/AIDS, law and human rights: action to combat HIV/AIDS in view of its devastating human, economic and social impact* (<http://www.unaids.org/publications/documents/human>). Geneva, UNAIDS, 1999 (accessed 24 April 2003).

Country experiences

Many models of HIV testing and counselling are being implemented in various countries and communities. Some of these are effective and should be scaled up; others are unethical, do not lead to health benefits and can traumatize and disable those tested. Examples of best practices regarding HIV testing and counselling models urgently need to be documented and disseminated. Any scaling up of HIV testing and counselling in the circumstances outlined above should lead to general improvement in the medical ethics and efficacy surrounding current practice relating to HIV and any other conditions where informed consent, confidentiality, counselling and testing are at issue.

Experiences were presented on the implementation of widespread HIV testing and counselling and attempts to expand such services in three countries (Brazil, Zambia and Zimbabwe), each describing different contexts and priorities¹⁹.

In Brazil, the country's policy and practice of universal access to antiretroviral agents provide a vitally important context for the HIV testing and counselling that is implemented on a wide scale there. In this regard, Brazil is a showcase for a country's ability to purchase, manufacture and distribute antiretroviral therapy in resource-constrained settings. It is also a model in which to study the positively reinforcing and dynamic interrelationship between prevention, care and treatment. With almost universal access to treatment and a concomitant decrease in denial, stigma and discrimination, HIV testing and counselling has become a standard and essential part of prevention and care efforts. Experience in Brazil also demonstrates how HIV testing, in terms of regional and national infrastructure for testing, must be scaled up if prevention and care are to be carried out effectively. The overall costs of provision of testing, counselling and antiretroviral therapy have been recouped in terms of lower hospital care costs and the reduction of other social and economic losses arising from the illness and death of those living with HIV/AIDS²⁰⁻²¹.

Zambia represents a model of rapid expansion of VCT services, having gone from a few such services in nongovernmental organization and research sites in 1999 to some 100 sites nationwide in 2002. Each of Zambia's 73 districts now has at least one testing and counselling facility, and 185,892 clients have been tested and counselled. By 2004, the target is that at least 25% of sexually active Zambians will know their serostatus. Important lessons have been learned on the need for political commitment, the efficiency and costs of different models, the reasons for uptake and dropout, the effectiveness of referrals to other services, the involvement of community partners and operational challenges related to logistics, supplies and quality assurance.

In Zimbabwe, a high-prevalence country, community surveys indicated that 50-70% of adults believed themselves to be infected even though most were not. At the same time, about 90% were not aware of their actual HIV status. This combination of perception and reality resulted in little incentive to change behaviour. As the provision of HIV testing was very uneven across the country, an initiative to increase access to VCT was begun. Because public surveys indicated that people considered an HIV test to represent a new start in their lives, the initiative was called New Start. Under this initiative, VCT has been provided in public clinics, in AIDS service organizations, in private company clinics, in freestanding clinics and in outreach programmes. Research has shown that social marketing of the programme has been successful in increasing access and uptake as well as in decreasing stigma and discrimination. The performance of different models has been evaluated, and lessons have been learned from each model. These lessons will guide future efforts to scale up.

¹⁹ *The Brazilian experience on increasing access to HIV testing* by Marco Antônio de Ávila Vitória, Brazilian STD/AIDS Program, Ministry of Health, Brasilia, Brazil; *Voluntary counselling and testing: the Zambian experience* by Francis Kasolo, Co-ordinator, Zambia VCT Service, Zambian National Programme, Lusaka, Zambia; and *New start VCT program: lessons learned* by Patrick Osewe, US Agency for International Development, Harare, Zimbabwe. Available on request from WHO.

²⁰ Chequer P et al. Access to antiretroviral treatment in Latin American countries and the Caribbean. *AIDS*, 2002, 16(Suppl 3): S50-S57.

²¹ Galvao J. Access to antiretroviral drugs in Brazil. *Lancet*, 2002, 360 (Issue 9348): 1862-1865.

Conclusions and next steps

The epidemic continues to evolve, requiring that responses not only keep up with its changing face but also anticipate its future demands. Within this evolution, the last few years have seen dramatic changes in the political and care landscapes of the epidemic. Health systems increasingly have something to offer those living with HIV/AIDS. There are real opportunities to decrease stigma and denial and to meet the societal demand for treatment and care. Nevertheless, seizing these opportunities requires that people know whether they are HIV positive or negative and be able and willing to undergo HIV testing and counselling procedures.

In this context, enormous numbers of people need knowledge of their HIV status, and in the near future, millions should be offered HIV testing and counselling under conditions that will help them to benefit their health and enhance their lives. Increasing opportunities to access treatment are now presented in a variety of settings.

In light of these developments, the participants felt that it is time to move beyond a single or rigid model of the provision of HIV testing and counselling. A variety of ethical, innovative, pragmatic and effective methods need to be developed to provide HIV testing and counselling in different settings. Within these settings, HIV testing and counselling should become more normalized and should be offered as standard practice: when requested to assist in preventing the transmission or acquisition of HIV; where medically indicated in the context of clinical care; or for preventing infection in mothers and infants. Although the offer of an HIV test may become standard under certain circumstances, it should still be performed with informed consent. The process by which informed consent is obtained will necessarily vary according to service delivery setting but is acceptable as long as there is sufficient information, understanding and choice.

However, much work remains to be done to significantly increase access to HIV testing and counselling. Priority tasks include documenting currently effective models, finding ways to support countries and communities to scale up, improving the efficacy and ethics of testing and counselling procedures in public and private sectors and ensuring the linkage between testing and counselling and treatment, care and support.

Several difficult challenges in the expansion of HIV testing and counselling need to be explored further: how to increase access to testing for minors and marginalized groups, how to improve the uptake and case-holding for women in family planning and antenatal care, how to get partners and men more responsibly involved in HIV testing and counselling processes, how to approach premarital testing and how to best use rapid testing and home-testing.

WHO and the participants are committed to continue to work together to support an urgent and dramatic increase in access to HIV testing and counselling services so that many more people can know their HIV status, can better avoid becoming infected if HIV negative and, if HIV positive, can benefit from care, treatment and support.

Annex 1

List of participants

Kevin De Cock

Director, CDC Kenya
National Center for HIV, STD and TB Prevention
Nairobi

KENYA

Alex Coutinho (unable to attend)

Chief Executive Officer
The AIDS Support Organization (TASO)
Kampala

UGANDA

Mandeep Dhaliwal

The International HIV/AIDS Alliance
Brighton

UNITED KINGDOM

Anand Grover

Lawyers Collective
Mumbai/Bombay

INDIA

Sofia Gruskin

International Health & Human Rights Programme
Francois-Xavier Bagnoud Centre
Harvard School for Public Health
Boston

UNITED STATES

R.C. Hitimana-Lukanika

Director
AIDS Information Center
Kampala

UGANDA

Claudes Kamenga

Regional Senior Technical Advisor
Family Health International
Accra

GHANA

Francis Kasolo

Co-ordinator, Zambia VCT Service
Virology Laboratory
Lusaka

ZAMBIA

Reidar Lie

Department of Philosophy
University of Bergen

NORWAY

Jean-Elie Malkin

Directeur Médical
Fonds de Solidarité Therapeutique International
Paris

FRANCE

Dorothy Mbori-Ngacha

Senior Lecturer
Department of Paediatrics
University of Nairobi
Nairobi

KENYA

Pren Naidoo

Manager
Central District TB/HIV Pilot Site
Cape Town,

SOUTH AFRICA

Ngongo Ngashi (unable to attend)

Ministry of Health
Family Health Division
Gaborone

BOTSWANA

Michael Sweat

Associate Professor of International Health
Johns Hopkins University
Bloomberg School of Public Health
Baltimore,

UNITED STATES

Prawate Tantipiwatanaskul (unable to attend)

Bureau of Mental Health
Technical Development Department of Mental Health
Nonthaburi

THAILAND

Annex 1

List of participants

Susan Timberlake (*rapporteur*)

Timber Dance Farm
Athens, GA

UNITED STATES

Marco Antônio de Ávila Vitória

Assessor Técnico da Unidade de Diagnóstico,
Assistência e Tratamento
Coordenação Nacional de DST e Aids
Ministério da Saúde
Brasília

BRAZIL

Beatrice Were

Executive Coordinator
International Community of Women Living with
HIV/AIDS
London,

UNITED KINGDOM

COLLABORATING AGENCIES

Charlene Brown

AAAS Fellow/Technical Advisor, VCT
US Agency for International Development
Washington,

UNITED STATES

Bess Miller

Associate Director for TB/HIV Prevention and Care
Global AIDS Program
Centers for Disease Control and Prevention
Atlanta,

UNITED STATES

Patrick Osewe

US Agency for International Development
Harare

ZIMBABWE

R.J. Simonds

Chief, Prevention Team
Global AIDS Program
Centers for Disease Control and Prevention
Atlanta,

UNITED STATES

WHO

• **Monica Beg**

• **Ties Boerma**

• **Christine Burgess**

• **Siobhan Crowley**

• **René Ekpini**

• **Massimo Ghidinelli**

• **Abiola Johnson**

• **Scott McGill**

• **Buhle Ncube (WHO Regional Office for Africa)**

• **Paul Nunn**

• **Virginia O'Dell**

• **Kevin O'Reilly**

• **Jos Perriens**

• **George Schmid**

• **Bernhard Schwartländer**

• **Kenji Tamura**

• **Isabelle de Zoysa**

OTHER UNITED NATIONS AGENCIES

Catherine Hankins

Associate Director, Strategic Information & Chief
Scientific Advisor

UNAIDS

Geneva

SWITZERLAND

Mariana Iurcovich

Advisor, VCT HIV/AIDS

PD/Health Section

UNICEF

New York,

UNITED STATES

David Miller

Country Programme Advisor

UNAIDS

New Delhi

INDIA

Annex 2. Agenda

Day 1

Tuesday, 19 November

Chairperson :
Claudes Kamenga

Welcome

Public health imperatives and challenges
in the context of HIV/AIDS

Bernhard Schwartländer

Increasing access to HIV testing and counselling :
looking back, moving forward
Objectives and expected outcomes

Isabelle de Zoysa

Estimating the need for HIV testing and counselling

Kevin O'Reilly

Discussion

Ethical considerations and informed
consent procedures

Reidar Lie

Discussion

Issues for provision of HIV testing & counselling
services in different situations :
guidance for breakout sessions

Isabelle de Zoysa

Breakout sessions

A. Diagnostic HIV testing in clinical care settings

Chairperson : Pren Naidoo

B. HIV testing in the context of prevention
of mother-to-child transmission programmes

Chairperson: Dorothy Mbori-Ngacha

C. HIV testing and counselling for HIV prevention

Chairperson : R.J. Simonds

Day 2

Wednesday, 20 November

Chairperson :
Mandeep Dhaliwal

Feedback of day 1 breakout sessions

Discussion and summary

**Meeting national goals and strategies
for scaling up : country experiences**

Thailand :

Prawate Tantipiwatanaskul

Brazil :

Marco Antônio de Ávila Vitória

Zimbabwe :

Patrick Osewe

Zambia :

Francis Kasolo

Annex 2. Agenda

Discussion

Costing HIV testing and counselling

Michael Sweat

Discussion

Developing a supportive policy and social environment

*David Miller
and Anand Grover*

Breakout sessions

Day 3

Thursday, 21 November

**Chairperson :
*Kevin De Cock***

Feedback of breakout sessions

Discussion and summary

Building consensus on guiding principles
and actions

Defining the components of a «road map»
for increasing access to HIV testing
and counselling

Closing remarks

Kevin O'Reilly

Close