

# The Role of Human Rights in Ensuring Universal Access to HIV Testing and Counselling

Report of a meeting sponsored by the World Health Organization, the Joint United Nations Programme on HIV/AIDS, and the Open Society Institute

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and the Open Society Institute

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*This report was drafted by the meeting rapporteur, Joanne Csete. It was finalized by the Open Society Institute's Public Health Program, the Secretariat of the Joint United Nations Programme on HIV/AIDS (UNAIDS Secretariat) and the World Health Organization.*

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## [1] SUMMARY

The 2007 WHO/UNAIDS guidance on provider-initiated HIV testing and counselling (PITC) specifies measures to ensure an environment conducive to human rights protections in PITC scale-up. Available evidence on the PITC experience thus far indicates that human rights elements of testing and counselling are neglected in policy and practice in many settings. The purpose of this meeting was to identify ways to bridge this gap between guidance and implementation. Participants were charged with identifying high-priority, concrete and feasible actions to overcome barriers to rights-based policy and practice in the scale-up of HIV testing and counselling. Overcoming these barriers would achieve both protection of human rights and expansion of testing and counselling as a gateway to treatment and would thus advance the right to health.

Discussions of human rights in HIV testing frequently focus on the “three C” elements of counselling, confidentiality and informed consent. However, the PITC guidelines and the discussion of experts in this meeting underscore the importance of a more expansive notion of respecting, protecting and fulfilling human rights in HIV testing and counselling. Other important elements include ensuring that testing is linked to treatment, care and support; ensuring that services are delivered without discrimination; meaningful participation of users of services in decision-making about the design, implementation and evaluation of HIV services; a supportive social, legal and policy framework that helps protect people from potential harms associated with disclosure of HIV-positive status; and mechanisms of redress for people whose rights are infringed in HIV testing. It was recognized that implementing this range of human rights elements is very challenging, particularly in countries where the language of human rights is resisted or little used in policy discussions. Nonetheless, meeting participants cited progress with respect to some of these elements and identified many possible avenues of further progress.

Much of the discussion focused on political and systemic barriers to rights-based testing and counselling. According to the discussions, barriers identified can be grouped in the following general categories:

- Resistance to human rights language and lack of a culture of patients’ rights;
- Focus on number of people tested as the main indicator of success of testing and counselling, with a corresponding lack of focus on process and outcomes related to human rights;
- Lack of appreciation in testing programmes and policies for the fact that women may be fearful of consequences of being known to be HIV-positive and afraid to question health professionals and other elements of the social context that affect the human rights vulnerability of people living with HIV. Similar concerns apply to key populations such as men who have sex with men, sex workers, people who use drugs and prisoners;
- Rights-unfriendly attitudes and practices of health care providers;

- Lack of investment in mechanisms by which to monitor the outcomes of testing and counselling (short-, medium- and long-term);
- Differing or inconsistent testing and counselling guidelines at different levels of government and among the various agencies active in the area;
- Lack of mechanisms of redress for those whose rights are violated in testing and counselling;
- Working conditions and health systems challenges that make it difficult for health workers to comply with human rights standards.

Some of these systemic barriers also have technical elements, and participants identified a number of other barriers that are technical in nature and may be found in some settings, such as the following:

- Lack of information on human rights, including reproductive rights, for persons using HIV testing services;
- Lack of access to peer counsellors or others who understand the realities faced by users of services;
- Logistic constraints for people who must pay for transportation to reach HIV services or who need assistance for child care;
- Lack of simple quality-control mechanisms such as exit interviews to capture the testing and counselling experience from the perspective of the users of services;
- Conditions that lead to health care providers being overworked, undercompensated, undersupported emotionally, and without the tools to reflect on and evaluate their own performance.

A wide range of recommendations for action emerged from discussions at the meeting. The essential elements of human rights-based practice in HIV care and all health services—participation, transparency, accountability, respectfulness, equity and protection from abuse—were important themes throughout the discussions and are reflected in the actions and strategies proposed. These include the following:

- Expand the evidence base on how people experience testing and counselling and on the health impact of human rights-based policies and practices;
- Shift the focus from number tested as the key outcome indicator of PITC and other HIV testing to number who experience positive health outcomes of testing and counselling, including access to treatment;
- Build understanding and awareness among donors of the importance—in both public health and justice terms—of strengthening human rights protections in HIV testing and counselling;
- Improve the capacity of health care workers to provide rights-based care;
- Support communities to mobilize and demand human rights protections in HIV testing and counselling;
- Establish international guidelines for HIV testing and counselling outside health services as governments are turning to door-to-door testing,

campaigns or testing days and other means of scaling up testing for which guidance and human rights standards have not been developed;

- Address or clarify any perceived inconsistencies in policy and guidelines related to human rights and HIV testing and counselling;
- Expand monitoring (including by communities), quality control measures and avenues of redress in HIV testing and counselling;
- Create a space to share best practices, research, indicators, training tools and codes of conduct.

Participants noted the ways in which their respective institutions could help move these actions forward, including making the most of platforms at the 2010 International AIDS Conference, which will have a focus on human rights and HIV/AIDS.

## **[2] OBJECTIVE OF THE MEETING**

The main objective of the meeting was to bridge the gap between existing HIV testing and counselling guidance and implementation to ensure the human rights protections in the HIV testing and counselling scale-up that are necessary to achieve universal access to comprehensive HIV services. It was hoped that the participants would reach consensus on concrete strategies and specific activities to overcome two types of barriers to ensuring human rights in the practice of HIV testing and counselling: political/systemic barriers and technical barriers.

## **[3] THE CHALLENGE OF RIGHTS-CENTERED SCALE-UP OF HIV TESTING AND COUNSELING: LAYING OUT THE ISSUES**

Opening sessions highlighted general concerns of the sponsoring organizations and participants in ensuring that human rights are respected, protected and fulfilled in the scale-up of HIV testing and counselling. It was noted that the May 2007 WHO/UNAIDS guidance on provider-initiated testing and counselling has strong recommendations for ensuring a conducive environment for human rights protections as part of PITC scale-up. These include not only a focus on the “three Cs” of confidentiality, informed consent and counselling, but also recommended actions to address stigma, discrimination and abusive practices, including means of monitoring outcomes as well as mechanisms of redress for those who experience abuse in health services. The focus of the meeting was not whether to implement measures to ensure rights-friendly testing and counselling, but how to do so.

While progress reports on universal access have shown some improvement in the uptake of HIV testing and counselling, much remains unknown about the quality of the testing and counselling experience, who is excluded from testing and counselling and why, and how much factors such as fear, stigma, unaffordability of tests, and insensitive and non-rights-respecting attitudes and practices in health facilities



impede progress toward universal access. Moreover, ensuring links between testing and treatment, care and support is a major challenge, as is understanding the lived experiences of people when they know and disclose their HIV status. The UNAIDS Outcome Framework gives priority to actions to reduce stigma and discrimination and remove punitive laws, policies and practices that can contribute to human rights abuses. Laws that may be interpreted as requiring testing and also disclosure of HIV status in some situations and laws that criminalize HIV transmission and exposure may undermine the desire to consent to testing and to seek other HIV services.

Meeting participants pointed to their own experiences with human rights-unfriendly policies and practices in HIV testing and counselling services in some countries. For example, a participant noted that in rural India where she works, HIV testing may be effectively mandatory in that women are not permitted to give birth in government hospitals without a test result, and private hospitals are often unaffordable or unwilling to give care to HIV-positive pregnant women. In one qualitative study in South Africa, it was noted that cultural factors may make some women reluctant to reveal that they are pregnant or to get tested for HIV. In addition, as in India, some women may effectively face HIV testing as an obligatory condition of receiving maternity services. Moreover, HIV testing may sometimes be presented to them as “for the baby” rather than a matter of their own health. Some women in these cases reported fearing the health system because of the harshness and condemnatory attitudes they face from health workers. Participants reported that in their experiences, HIV-positive women in India, South Africa and other settings are judged harshly for being pregnant.

### **[3.1] Case studies**

There is a need for more research that goes beyond the numbers of people tested for HIV and examines people’s testing and counselling experiences and whether testing and counselling leads to treatment and better health outcomes. There is also a need for improved understanding of the gap between *policies* that provide human rights protections and *practices* that may undermine them. Priority research topics include the impact on women of various HIV testing and counselling models, factors determining access to other HIV prevention and treatment/care services, and negative repercussions of testing and counselling and disclosure, including violence, blame, abandonment and loss of economic support.

Building on an OSI-commissioned paper (“HIV Testing During Pregnancy: A Literature and Policy Review”) by University of North Carolina (UNC) researchers, the Open Society Institute supported UNC and HealthRight International to develop case studies on the implementation of HIV testing and counselling of pregnant women in Kenya, South Africa and Ukraine. Community-based organizations and networks of people living with HIV simultaneously collected narratives on women’s testing and counselling experiences, complementing the work of the researchers and strengthening their own advocacy.

Durban, South Africa (presenter – Allison Groves, UNC): South Africa has an explicitly human rights-oriented policy on HIV testing and counselling of pregnant

women, confirming the importance of the three Cs, calling for both written and oral consent to HIV tests, and indicating that pre-test information is a prerequisite to obtaining consent and that post-test counselling is required. The case presented from an antenatal facility in Durban showed that even as women experienced the clinic as a relatively supportive environment, many of them were tested without written consent (in contravention of the national policy), and many understood the HIV test to be obligatory for pregnant women. Groves observed that in this setting there may be a fine line “between coercion and persuasive counselling” when it comes to the choice of whether to have an HIV test. Participants stressed that this clinic may have implemented rights-centred elements of the national policy better than many others, and its experience is not generalizable.

Donetsk region, Ukraine (presenter – Halyna Skipalska): Preliminary results of the HealthRight International study in two sites in Ukraine were based on interviews of a small number of pregnant women. Skipalska noted that the case raises a number of issues, including that women perceived or were told that HIV testing was mandatory; women were not asked for their informed consent or were not aware that they were being tested for HIV; and women said that two or more staff members of the health facility were present during their counselling and testing, which raises privacy concerns. In addition, women who used illicit drugs were mistreated, counsellors were lacking in motivation, the hours of testing centres were inconvenient, and it took a long time to get test results. This study is continuing.

### **[3.2] Policy and literature reviews**

Reviews of existing PITC policies and of published literature on PITC policy and practice were also presented.

AIDSTAR policy review (presenter – Maria Claudia Escobar, AIDSTAR): The USAID-funded AIDSTAR-One project examined the PITC policies of 28 PEPFAR countries, mostly in Africa. Half the countries had PITC policies of some kind, with governments noting the importance of provider initiation for increasing access to testing, counselling and treatment. Some concerns raised in this overview are the vagueness of policies, the lack of attention in policies to the rights of people tested, the lack of protections for health care providers, and the lack of clear operational guidance to accompany the policies. In addition, the lack of mechanisms for redress for people whose rights are violated in testing and counselling is a major concern, as is loss to follow-up where rapid tests are not used and linked to treatment and care more broadly. Escobar noted that in many countries, these policies take the form of directives not resulting from consultative processes.

PITC literature review (presenters – Sofia Gruskin, Harvard University School of Public Health, and Leigh Higgins, independent consultant): Gruskin and Higgins presented preliminary results of a scan of national policies, guidelines, training materials, professional commentaries, and peer-reviewed articles that address strategies to secure human rights protections in the context of HIV testing and counselling, as well as their analysis of gaps in existing materials. The review covered peer-reviewed and grey literature since 2006.

The presenters noted that relatively few of the national policies on HIV testing and counselling inspired by the PITC guidance have an explicit focus on human rights. Stigma and discrimination are generally acknowledged but insufficiently addressed in national policies. Prof. Gruskin noted the need for human rights elements to be represented among outcome indicators in the monitoring of PITC programmes. She also emphasized that many policies fail to encourage attention and support to meeting the needs of vulnerable populations. In the discussion of this presentation, it was noted that there continues to be a claim in some quarters that normalizing HIV testing and making it more routine will more or less “automatically reduce stigma”, a claim that has not been rigorously tested. Participants also noted that it is unfortunate that questions of gender and power are so little represented in the PITC literature.

#### **[4] THE FULL RANGE OF HUMAN RIGHTS ISSUES RELATED TO HIV TESTING AND COUNSELLING**

A consideration of the full range of human rights concerns related to HIV testing and counselling was useful to inform discussions in the meeting. The public health importance of human rights protections is noted explicitly in the 2007 PITC guidance:

Positive outcomes are most likely when HIV testing...is confidential and is accompanied by counselling and informed consent, staff are adequately trained, the person undergoing the test is offered or referred to appropriate follow-up services, and an adequate social, policy and legal framework is in place to prevent discrimination (p 30).

The “three C’s” usually figure prominently in discussions of human rights and HIV testing, but as the quotation above suggests, there is a wider range of human rights elements that should be part of HIV testing policy and practice. The meeting used the following list of ten elements (compiled by Jonathan Cohen, director of OSI’s Law and Health Initiative), derived directly from provisions of human rights treaties, which informed subsequent discussions of barriers to rights-based scale-up of HIV testing.

##### **[4.1] Right to health**

HIV testing and counselling must be part of the “highest attainable standard” of health in all types of epidemics, as specified in the PITC guidance. These services should meet standards of availability, accessibility, acceptability and quality, as those terms are defined in the General Comment on the right to health of the Committee on Economic, Social and Cultural Rights, which is an authoritative guide to realizing the right to health.<sup>1</sup> Criminalized and socially marginalized persons unlikely to be

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<sup>1</sup> UN Committee on Economic, Social and Cultural Rights. General Comment no. 14: the right to the highest attainable standard of health (art. 12). UN doc. E/C.12/2000/4, 11 August 2000.

regular users of government health facilities should have access to respectful and unthreatening voluntary testing and counselling.

**[4.2] Consent**

People must have the chance to decline an HIV test if they do not want it. Routinizing the offer of HIV testing should not mean cutting corners on consent or sliding toward coercive practices or attitudes. Governments should have clear legal and policy frameworks for consent, including for minors.

**[4.3] Confidentiality**

Training of health care providers should emphasize their responsibility to maintain confidentiality of test results. UNAIDS and WHO encourage voluntary disclosure of HIV status and ethical partner notification and counselling. National policies and ethical codes should be developed to guide partner notification in clearly defined circumstances.

**[4.4] Privacy**

Informed consent should be sought and given in a private setting. Post-test counselling and other communication relating to HIV status should take place away from people not involved with the care of the person tested and counselled.

**[4.5] Pre- and post-test counselling**

Post-test counselling is an integral component of HIV testing, regardless of the test result. While pre-test information, according to the PITC guidelines, can be given in individual or group sessions, post-test counselling should be private and should allow the person tested to ask questions freely.

**[4.6] Non-discrimination**

Optimal delivery of HIV testing and counselling requires that laws and policies be in place and enforced against discrimination based on HIV status, risk behaviour, gender and sexual orientation. Declining an HIV test should not result in reduced quality or denial of services that do not depend on knowledge of HIV status. Policy and practices should be in place to guard against ill treatment of or discrimination against persons living with HIV in health facilities. Providers should be taught about the need for non-discriminatory, non-judgmental attitudes.

**[4.7] Link to treatment and other services**

Testing and counselling must be a link to comprehensive HIV prevention, treatment, care and support services. In places where antiretroviral treatment (ART) is not available, care short of ART can be useful. Although access to ART should not be an absolute prerequisite for the implementation of PITC, there should be a reasonable expectation that it will become available as part of a national plan to achieve universal access to treatment.

**[4.8] Protection from harm**

Where there are high levels of stigma and discrimination and poor capacity to implement HIV testing under conditions of informed consent, confidentiality and

adequate counselling, these shortcomings should be addressed prior to PITC implementation. Efforts must be made to ensure that a supportive social, policy and legal framework is in place to maximize positive outcomes and minimize harm potential harms for those tested. Health care providers should be trained on the urgency of protections for persons susceptible to coercion, discrimination, violence, abandonment, incarceration and other negative consequences of disclosure of HIV-positive status. Women are often more likely than men to experience these outcomes.

#### **[4.9] Participation**

HIV testing and counselling should be undertaken in consultation with key stakeholders, including civil society groups and people living with HIV. Involving most-at-risk populations in the development of HIV testing and counselling protocols and in monitoring and evaluation of services will help to ensure that the most appropriate and acceptable practices are instituted.

#### **[4.10] Redress**

Health facilities should develop codes of conduct for health service providers and methods of redress for patients whose rights are infringed. Appointment of an independent ombudsman or patient advocate should be considered.

#### **[4.11] Discussion**

Anne Gathumbi of the Open Society Initiative for East Africa and Roger Staub of the Federal Office of Public Health in Switzerland introduced the discussion of political and systemic barriers to rights-based HIV testing and counselling with reference to experiences in their countries. In discussing whether it is realistic to expect PITC and other testing and counselling services to incorporate all these human rights concerns, Gathumbi noted that in many countries, the term “human rights” itself will be seen as threatening and may impede policy consideration of informed consent and other basic elements of PITC. A participant suggested that human rights ideas should always be spoken of as essential to public health outcomes and not outside that context. It was also noted that donors may be as focused as governments on higher numbers of tests as the main outcome of programmes, and may be just as disinclined as governments to give priority to human rights elements of HIV testing. Others expressed concerns that the reality of the workload of health workers in facilities doing testing is such that thorough counselling or delivery of adequate pre-test information and an unhurried informed consent process may be too much to expect.

Even in a setting such as Switzerland, with adequately funded and high-quality health services and a political environment respectful of rights, Staub noted that there are barriers at several levels to a human rights-centred approach to testing. Among health professionals, paternalism and “knowing best what’s good for the patient” may undermine human rights thinking. In addition, there may still be a strong bias among health experts to treat HIV like more contagious infectious illnesses of the pre-AIDS era—that is, at all costs, detect, treat and eliminate—and these ideas are sometimes hard to dislodge in favour of a concern about the rights of

people living with the illness. Experience with other infectious diseases may also lead health professionals to suppose that it is always better for patients to know their disease status than not to know, without necessarily reflecting on possible adverse outcomes that may attach to knowledge of HIV status compared to other illnesses.

Participants noted that for women, HIV testing without human rights protections can be experienced as a regime of power and subordination. The same institutions that may coerce or may be perceived by HIV-positive women as coercive with respect to using contraception, or even being sterilized, will be seen as coercing women into HIV testing if services are not offered respectfully. Moreover, as one participant noted, it is widely accepted in some settings that women and children are not supposed to know about or indeed have rights, and those who try to assert them may face repercussions that impede their ability to seek health services.

Participants agreed on the importance of monitoring HIV testing and counselling. A system should be put in place to monitor social, health-related and legal outcomes of HIV testing and counselling and to ensure referral to proper support mechanisms to address negative outcomes.

## **[5] IDENTIFYING POLITICAL AND SYSTEMIC BARRIERS TO RIGHTS-BASED HIV TESTING AND COUNSELLING**

Participants were charged to identify important political and systemic barriers to rights-based PITC implementation and to recommend measures to address these barriers. Political and systemic barriers were defined as those that would impede implementation of human rights protections in HIV testing even where such protections were technically feasible – that is, knowledge and skills existed to implement them. The barriers discussed below are not separate and independent challenges, but rather overlap considerably, as do solutions related to them.

### **[5.1] Resistance to human rights language and lack of currency of ideas of patients' rights**

There was considerable discussion about the social, legal, cultural and communications challenges related to overcoming resistance to human rights ideas and language in policy and practice associated with HIV testing and counselling. Governments often reject human rights as a framework for health policy discussion. In some places human rights concepts may be addressed at the level of the “elite”, but are otherwise not made central to policy discussions or even civil society concerns. Health professionals are not usually trained in human rights, and the health services culture (in many cases dominated by hierarchy and placing a high value on technical knowledge) is not conducive to putting respect for the rights of users of health services at the centre of design, implementation and evaluation of services.

### Proposed solutions

- a) Create a culture of patients' rights with a focus on concrete entitlements and community mobilization, building on lessons from the success of rights-based advocacy related to HIV treatment. Many strategies and actions were suggested toward this end, including the following:
- Mass media-based, compelling local language public awareness campaigns;
  - Improved health worker training on patients' rights (though a participant noted that people living with HIV have struggled not to be referred to as patients, and expressed concern that "patients' rights" language would remedicalize the HIV discourse);
  - Efforts at "naming and shaming" related to violations of the rights of people using health services;
  - Establishment of effective mechanisms of redress for users of health services whose rights are violated (see barrier 5.6 below), as well as financial assistance for patient support groups and community-based patient watchdog groups;
  - Development and dissemination of patient charters, such as those developed in Uganda, South Africa and Kenya, and of related public service charters for health workers;
  - Ensuring that guidelines for PITC design, implementation and evaluation include indicators related to the rights of users of health services;
  - Formal linkages between health facilities and community-based organizations that provide a monitoring and support function, including exit interviews and referrals.

Participants noted that WHO and UNAIDS could play an important role in urging governments and donors to be active in or facilitate civil society involvement in such efforts.

- b) In policy discussions and advocacy, use language of "quality assurance" and the General Comment language of availability, accessibility, affordability, acceptability and quality—notions that embody human rights principles but may be more acceptable to policymakers than human rights terms that are not always well understood.
- c) The language and framework of medical ethics, possibly less threatening than human rights, would include some of the central rights concerns in HIV testing and counselling and may be more likely to engage health professionals and their associations. One suggestion was for WHO to urge the World Medical Association to issue guidance on HIV testing and counselling in the language of medical ethics. Participants agreed on the importance of more and better capacity-building on normative issues for health providers, which might be done through case studies showing human rights in practical terms, outreach to opinion leaders among

health providers, and improving curricula of professional schools. Some participants noted that engaging medical associations is a “top-down” strategy that must be complemented by efforts to strengthen community-based human rights advocacy and awareness.

- d) Monitor budgets of national plans of action and work with donors to ensure that resources are made available for and allocated to human rights elements of PITC. Encourage donors to include human rights activities explicitly in grant proposal guidelines and requirements. The recent work of the Global Fund to Fight AIDS, Tuberculosis and Malaria to improve a focus on gender-related rights in country proposals may be a promising approach.

**[5.2] Number of people tested as indicator of success (among donors and governments) and lack of understanding of the importance of human rights to the attainment of universal access**

Discussion at the meeting returned often to the structural problem of the focus on number of people tested as the main performance indicator of HIV testing and counselling. Participants were struck by figures cited from Asia, for example, indicating large increases in numbers of people tested but only a modest increase in numbers receiving treatment. In the discussion, some participants said this result typified a failure to appreciate that the link between HIV testing and counselling on the one hand and the right to treatment on the other is a matter of human rights as well as a condition for universal access. There are very few existing mechanisms for donor accountability on human rights related to testing. Participants also raised the related concern that PITC guidelines are misinterpreted in many settings as endorsing mandatory testing.

**Proposed solutions**

- a) Redefine PITC as PITCT—that is, provider-initiated testing, counselling and treatment—as part of a campaign for awareness of effective and high-quality treatment as the ultimate goal of testing and counselling. This campaign would help health authorities and donors to understand rates of testing and counselling as only one process indicator that needs to be complemented by ultimate outcome indicators related to treatment. It would also reinforce the importance of high-quality treatment, particularly in places with a staggering array of fake cures and false health claims of non-ARV therapies, and limited to no government action to challenge such fake cures or false claims. In addition, demand for effective treatment would generate demand for testing and counselling.
- b) Strengthen the evidence base on the health impact of respect, protection and fulfilment of human rights with respect to HIV testing and counselling and universal access to HIV services. It is important to document what happens to people once they are tested and counselled. There was considerable discussion in the meeting about the kind of evidence that would be convincing to governments and donors. A review by UNAIDS of



HIV-related human rights programmes in 56 countries is an example of the evidence needed. This review analysed the extent to which the following programmes have been planned, costed, budgeted and evaluated in national AIDS programmes:

- Reduction of HIV-related stigma and discrimination;
- HIV-related legal services for people living with HIV and those at risk;
- Training of service providers (health care workers, judiciary, police) on non-discrimination, informed consent and confidentiality;
- Legal audit and law reform programmes;
- “Know your rights” campaigns;
- Programmes to empower women and reduce gender-based violence.

Participants noted that it would be useful to have more research on the real-life ways in which PITC is experienced by people, the extent and nature of abuses that may occur, and the ways in which they are being addressed. It would also be important to build a body of evidence on good practices and effective rights-based approaches to testing.

- c) A donor dialogue that would enable evidence (as in solution b) and complementary indicators (as in solution a) to be discussed in depth, including in the context of strengthening health systems and empowering health care providers.
- d) Include as an indicator of progress to universal access not only how many people are tested but also how many people of those tested receive care and treatment. Inclusion of indicators beyond number of tests would be important in the report on progress toward universal access scheduled for 2011. It was noted that it is not possible to change the UNGASS reporting indicators for 2010, but there may be a possibility of establishing new indicators for the period leading up to 2015 and beyond. Tracking users of health systems – from testing and counselling through to treatment outcomes – is beyond the current capacity of monitoring systems in many countries, but efforts to overcome this capacity constraint could be part of discussions with donors and civil society groups. WHO’s 2009 publication “HIV testing, treatment and prevention: generic tools for operational research” may suggest useful indicators for future monitoring and evaluation. There may also be opportunities for indicators beyond number of persons tested to be considered in Global Fund midterm reviews. In addition, governments should report on relevant policy indicators.

**[5.3] Lack of appreciation for the social context—including risk of human rights abuse—of HIV testing, especially lack of attention to subordination of women**

Discussion in the meeting returned frequently to the observation that HIV testing and counselling must be seen in the context of power relations shaped by gender. Most people tested through PITC are women. As noted above, women may

experience HIV testing as one more reflection of the disempowerment they face in their daily lives, particularly if attitudes and practices in health facilities do not embody respect for women and efforts to correct power imbalances. Pregnant women may be particularly disempowered and vulnerable to coercion and abusive attitudes. While it was recognized that addressing subordination of women is a long-term challenge, it is unacceptable not to strive to find feasible ways to empower women with respect to their access to and use of HIV services. This is another factor that might usefully figure in Global Fund midterm reviews.

Proposed solutions

- a) Establish mechanisms for ensuring meaningful participation of women, including women who have already experienced PITC, in design, implementation and evaluation of PITC programmes and in research related to PITC.
- b) Establish a legal framework for women's rights, including women's right to non-discriminatory access to both comprehensive HIV services and reproductive health services and information.
- c) Strengthen efforts to link HIV services to reproductive health services and information in ways that improve the access, affordability, acceptability and quality of both sets of services for all women.
- d) Strengthen efforts to improve awareness and attitudes of health professionals as noted below (barrier 5.4).

**[5.4] Rights-unfriendly attitudes and practices of health care providers**

Related closely to the gender-linked power questions noted above are questions of relations between health professionals and users of health services. As already mentioned, doctors and other health professionals may feel that they know what is best for patients and not perceive the need for meaningful consultation with them. The stature of doctors in some places may be such that a person with less education or a lower social status (e.g. women living in places with high gender inequality), would not dare to question a doctor's actions or advice. Even where this is not the case, health professionals by their attitude and demeanour can create an environment in which users of health services do not feel inclined to question recommendations or seek additional information. This is a particular liability with regard to HIV and other diseases related to sex and drugs, for which opportunities to ask questions of knowledgeable people are crucial and may be rare. Meeting participants noted further that in many countries, professional associations feed the culture of the inviolability of medical expertise and implicitly protect disrespectful attitudes and practices of doctors.

Proposed solutions

- a) Training for health professionals on rights-based practices (informed consent, confidentiality, non-discrimination, duty to treat), including in-service training and in their schooling and internships.
- b) Model codes of conduct for health professionals with systems of enforcement and monitoring.

- c) Well established and funded mechanisms that encourage health professionals to interact with community-based groups representing the concerns of users of health services.
- d) Clearer roll-out guidance for PITC that emphasizes ways to address paternalism and power dynamics in relations between health care providers and users of health services.

**[5.5] Inconsistent guidelines for PITC at international, national and local levels**

Participants noted that not only do some national guidelines (including the guidelines of the United States Centers for Disease Control) for PITC seem to differ in important respects from the WHO/UNAIDS guidelines, but private organizations working internationally have guidelines or training protocols that are different from UN recommendations. The differences in guidelines may confuse health care providers or lead to inconsistent practices, with each provider following the guidance and practices they know best. In addition, participants noted instances of inconsistencies in the interpretation of guidelines within the UN System itself and the guidance provided to countries.

Proposed solutions

- a) Document and address inconsistencies that may exist in testing and counselling guidelines of various service-providers.
- b) Depending on the significance of the differences among guidelines, WHO may consider convening a group, perhaps along the lines of the interagency body on mother-to-child transmission, to harmonize guidelines and disseminate harmonized guidance.
- c) If there are parts of the PITC guidance that seem particularly open to misinterpretation, WHO and UNAIDS should revisit those elements to find formulations that are clearer.
- d) In monitoring of universal access or other reporting mechanisms, include policy indicators that will help UN agencies monitor inconsistencies in policies.

**[5.6] Lack of mechanisms for redress for those whose rights are violated**

Although the PITC guidance explicitly urges governments to institute mechanisms for redress for people whose rights are violated as part of HIV testing and related activities, it is clear that such mechanisms are few. As meeting participants noted, there can be very extensive training of health care providers on rights-based practices and attitudes, but it is likely not to be completely effective without the “checks and balances” of a complaint mechanism that is seen as fair and efficacious by those using services.

Proposed solutions

- a) Complaint mechanisms for users of health services with power to make judgments and award damages or impose sanctions.
- b) Community-based watchdog groups that can monitor outcomes of testing and counselling and refer concerns to a complaint mechanism and help

ensure that the mechanism is sustained and functional. Such groups can also make public reports “naming and shaming” facilities where rights are not respected.

#### **[5.7] Weakness of health systems**

It was recognized repeatedly that health systems in many AIDS-affected countries are weak and face extraordinary resource and staffing constraints. Health care providers may be overworked, undercompensated, posted to unfavourable locations, and insufficiently supported psychologically in the difficult work they do. They may not have had adequate training for the provision of the range of services they provide. A number of the proposed solutions already noted would also address this concern. Health workers may also fear for their own health in settings where there is little access to infection control for tuberculosis or universal precautions for HIV.

### **[6] TECHNICAL BARRIERS TO RIGHTS-BASED PITC**

In addition to political and systemic barriers, participants were charged to identify technical barriers to rights-based PITC—that is, barriers that might be overcome without structural change—and to propose ways to address these barriers. Much of the discussion focused on ways to improve the practice of testing and counselling, including through various quality assurance and monitoring mechanisms.

As noted above, preliminary results from the Harvard University literature review indicated that tools for enhancing rights-centred elements of PITC are not widely reported in the peer-reviewed literature. Very few rigorous programme evaluations are in the literature, and also very few accounts—from the perspective of the health service provider or the person tested—of what happens in provider-initiated testing and counselling experiences. To enrich the discussion, several participants recounted experiences meant to improve rights-based PITC, including an extensive system of peer counsellors and supporters for pregnant women and sex workers in India, improved training of HIV counsellors in Kenya, and a focus on gender-based violence and access to legal services as part of HIV testing and counselling in South Africa.

A framework identifying opportunities for improvement based on the stages before, during and after the testing experience was proposed and fleshed out along the following lines:

#### **Before testing:**

- Ensure that users of health services know their health rights, including rights related to sexual and reproductive health.
- Pre-test information should include access to supportive peer counsellors or advocates—a chance for people about to be tested to speak with someone who understands their reality.

- Financial and logistical support for getting to a testing facility—child care, transportation, etc.

#### During testing

- Measures to ensure that counsellors and other health care providers (midwives, etc.) are supported with good training and decent work conditions and feel comfortable with human rights and ethical aspects of the testing and counselling process.
- Measures to ensure that one-on-one counselling is not abusive in any way
- Built-in monitoring and quality control—such as exit interviews or other measures.
- Measures to ensure infection control and universal precautions.

#### After testing

- Follow-up and effective links to care and treatment.
- Follow-up and peer support related to disclosure, stigma, etc., including with families and including dispute resolution services. (In countries where there is a law requiring disclosure within a certain period of time, this kind of follow-up, along with legal support, may be especially crucial.).
- Access to legal or paralegal services.
- Monitoring mechanisms in the community.

Many of these measures—including community-based monitoring, peer support for follow-up to testing, and legal service provision—would require significant capacity-building and financial support. Participants noted that building capacity in these areas is especially challenging in places where technical guidance on PITC has not even been explained to or put in the hands of all health workers in testing and counselling facilities. It was also noted that the “before-during-after” framework may need to be adapted to the reality that many people may have a first test, not disclose the results, take time to reflect on their situation, and have another test, and perhaps repeat the process again at another time. Participants also discussed whether dimensions of the framework could be adapted to HIV testing approaches other than PITC.

Much of the discussion focused on overcoming technical barriers through institutionalizing quality assurance standards and procedures together with improved monitoring and evaluation of PITC practices and policies. Improved quality assurance should involve many stakeholders—community-based monitors, training institutions in the health sector, health care providers in their own monitoring and self-reflection, users of services, professional and accrediting associations—along with national policies and commitments that help create a culture of quality assurance. The importance of outcome and monitoring indicators other than number of persons tested was highlighted again, as with regard to systemic barriers. WHO described its effort, now in progress, to develop a quality improvement framework (QIF) for HIV testing and counselling. As part of the QIF, a monitoring

and evaluation guide is exploring examples of indicators of quality of HIV testing and counselling and ways to collect and analyze quality data at the facility level and in consultation with the community. The QIF is meant to be a simple framework based on real experiences, suggesting a step-by-step approach to building a culture of quality in planning, design, implementation and evaluation of PITC activities.

## **[7] IDENTIFYING ACTIONS AND STRATEGIES FOR ADVANCING RIGHTS-BASED PITC**

With a view to advancing rights-based HIV testing and counselling, participants were charged with identifying high-priority, concrete, feasible actions for enhancing human rights protection, promotion and fulfilment in PITC, with respect to all of the barriers and issues discussed in the meeting. A wide-ranging discussion resulted in numerous recommendations that are summarized below. (Many of these echo the recommendations related to political and systemic barriers noted above.) The essential elements of human rights-based practice in HIV care and all health services—participation, transparency, accountability, respectfulness, equity and protection from abuse—were important themes throughout the discussions and are reflected in the actions and strategies proposed.

### **[7.1] Expanding the evidence base on actual practices in PITC and on the health impact of human rights-based policies and practices**

Participants expressed frustration over the fact that the PITC guidance has quite good recommended actions for human rights protections, but these actions are rarely implemented. The degree to which this failure of implementation results from lack of evidence of the effectiveness of these actions is not clear, but many in the meeting thought more such evidence would help mobilize resources to support rights-based activities. There was considerable discussion about the level of rigor needed in new research to generate this evidence, with agreement finally that there is a range of needs among donors, policy-makers and others for a range of types of research from peer-reviewed publications to well-presented and sharply focused NGO reports. Some specific ideas for generating evidence included the following:

- Rapid assessment of the ten recommended human rights elements in PITC programmes in selected facilities in selected countries with an eye to identifying deficits and making recommendations on how to improve practices and strengthen guidelines. This could be done in about a week per country with well trained researchers and a clear protocol. Others suggested similar assessments but possibly somewhat less rapid, to get detailed documentation of actual PITC practices in ten or so countries.
- Comparison of countries that have had some success with rights-based elements of PITC with others that have been less successful.
- Draw out best practices in consent procedures, counselling, complaint mechanisms, etc. from detailed case studies of PITC experience.

**[7.2] Shifting the focus from number tested as the key outcome indicator**

There was a strong consensus in the meeting that international organizations should find ways sooner rather than later—perhaps in 2010 reporting on universal access—to urge countries to report on indicators other than just the increase in the number of persons tested for HIV and increase in the number of testing centres. Such additional indicators could address the quality of the testing and counselling experience, and the extent to which people who access testing and counselling are linked to treatment. It was recognized, again, that the capacity for tracking people from testing to treatment is not well developed in many countries, but participants thought this was a barrier that should be tackled. Monitoring should also be developed to identify factors such as stigma, HIV-related provisions of criminal law, and fear of violence that may undermine motivation of people to agree to be tested or to follow-through with other measures after testing. Expanding the range of reported indicators would ideally happen as part of building a culture of quality improvement in testing and counselling and other HIV and health services.

**[7.3] Building the understanding and awareness of donors**

There was a strong consensus that donor awareness of and thus commitment to human rights elements of PITC is a major weakness that is susceptible to strategic action. Some thoughts for raising donor awareness included the following:

- Organize study tours or other ways for donors to experience first-hand the reality of PITC practices and experiences and to hear from community members as well as health care providers.
- Mobilize short (two-page) summaries for donors on human rights-based practices in PITC, and thus encourage them to learn about and choose among good practices in their funding decisions.
- International organizations, civil society and policy-makers should lobby donors to institute ways of encouraging those who receive their support to budget for human rights elements of PITC and feature them as central elements in their proposals and reports.
- A special “donor dialogue” event on human rights in HIV testing and counselling would be a platform for sharing new evidence and urging action on measures noted here.

**[7.4] Improving capacity of health care workers to provide rights-based care**

Participants noted that part of building the capacity of health care providers is understanding their constraints and reality, which has been neglected in research and reporting. An experience in Malawi was cited that showed that some health care providers live with great fear because they feel unprotected in the face of high levels of professional exposure to HIV, explaining somewhat the stigma and fear that they show to users of their services. Improved training of health workers, which should be designed with their meaningful participation, and improved quality control mechanisms (see next point) that assist health workers without overloading them should be important capacity-building strategies. Participants noted the particular importance of ensuring that health workers do not understand PITC as mandatory testing, an essential element in dispelling this idea among users of services. Some

participants said it might also be useful for health care providers themselves to go through PITC as users rather than providers of the service.

**[7.5] Expanding monitoring (including by civil society), quality control and avenues of redress**

Discussions in the meeting repeatedly emphasized the importance of involving civil society in monitoring of PITC, building capacity for that monitoring, and using that monitoring to improve accountability and quality of services. The urgent need to improve the capacity of community organizations to raise funds to be part of health service monitoring was also emphasized. It was also noted that free or affordable legal services, which are rarely available but can be crucial to ensuring the integrity of rights-based services, are most likely to be provided by civil society organizations that need financial support.

**[7.6] Improving coordination of sharing of information, communication, and rest of the above activities**

Participants called on international organizations and the Open Society Institute to consider establishing a coordinating mechanism for managing improved rights-based HIV testing and counselling and related sharing and management of information. A “knowledge network” would enable new research and documentation of experiences to be shared efficiently. A coordinating body could help define and implement a communications strategy for improving rights-centred practices and could identify and communicate research needs. It was suggested that the AIDS and Law Exchange ([www.aidslex.org](http://www.aidslex.org)) recently launched by the Canadian HIV/AIDS Legal Network might be a home for a knowledge network on this subject.

**[7.7] Strengthening leadership of international organizations**

Participants also called on WHO and UNAIDS to provide bold leadership on rights-based HIV testing and counselling in their interaction with donors, governments and civil society. It was noted that there is a widespread perception that the UN is pushing for everyone to be “tested at all costs”; PITC remains poorly understood in some places, and the human rights protections that are part of the guidance are especially underappreciated. As WHO continues to develop a quality improvement framework for HIV testing and counselling and as UNAIDS continues to advocate for human rights and removing punitive laws and policies, there are important opportunities for enhanced leadership in this area.

**[7.8] Guidance on non-PITC modes of HIV testing and counselling**

It was also noted at several points in the meeting that while the human rights elements of PITC are well described in the guidance, countries are turning to methods of promoting testing outside health facilities, including door-to-door and mobile testing, testing in markets and other community-based settings, and national campaigns or testing days. Participants stressed the urgent need for developing human rights-based guidance on HIV testing and counselling for these other modes of testing. WHO noted that its quality improvement framework (QIF) will pertain to all forms of HIV testing, not just PITC.



## [8] CONCLUSION

Human rights is both a cornerstone of the new UNAIDS Outcome Framework and the theme of the International AIDS Conference in Vienna in 2010. The conference will be an important platform for leadership and information sharing in all of the action areas noted above and more generally for advocating for support for human rights elements of HIV testing and counselling in health facilities and other settings. While audiences at the Vienna conference will be relatively knowledgeable about AIDS, there was agreement among meeting participants that even people steeped in HIV work should be re-energized around the urgent need to address barriers to rights-based HIV testing and counselling.

This meeting brought together representatives of diverse organizations and perspectives. In spite of differences, everyone brought to the table a sense of urgency around scaling up HIV testing and counselling as prerequisites to universal access to HIV treatment, care and support. The participants shared a frustration over the singular focus on number of persons tested in monitoring HIV testing and counselling, and brought many constructive ideas for renewed leadership and action toward strengthening human rights elements of testing and counselling in implementation and monitoring of services. Meeting participants renewed their commitment to strengthening these elements both to improve the process and enhance the likelihood of achieving universal access to HIV services. They urged that the various actors involved in HIV testing and counselling—implementers, researchers, funders, UN organizations and civil society members—seriously consider the recommendations from the meeting to ensure human rights in HIV testing and counselling, for both policy and practice.

## APPENDIX

# The Role of Human Rights in Ensuring Universal Access to HIV Testing and Counseling

October 12-13, 2009, Geneva, Switzerland  
Crowne Plaza Hotel, Nendaz Conference Room  
34, Route Francois-Peyrot

## AGENDA

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**Sponsors:** The Open Society Institute's (OSI) Public Health Program, the Secretariat of the Joint United Nations Programme on HIV/AIDS (UNAIDS Secretariat), the World Health Organization (WHO).

**Goal:** This meeting aims to bridge the gap between existing HIV testing and counseling guidance and implementation to ensure human rights in HIV testing and counseling scale-up. We hope to reach consensus on concrete strategies and specific activities to overcome two types of barriers and concerns to ensuring human rights in practice: political/systemic and technical.

### Monday, October 12, 2009

**8:30 a.m. Registration**

**9:00 a.m. Open and Welcome**

*Facilitator:* Josh Mintz (Cavanaugh, Hagan, Pierson & Mintz, Inc.)

- Welcome by OSI (Cynthia Eyakuze), UNAIDS (Susan Timberlake), and WHO (Ying-Ru Lo)
- Introductions
- Review of goals for the meeting (Jonathan Cohen- OSI)
- Overview of the agenda by the facilitator

**9:30 a.m. Why This Matters**

*Panelists:* Loon Gangte (Delhi Network of Positive People), Jenny Bell (Justice & Women), Eunice Oyiea (Wellcome Trust Research Program), Meena Seshu (Sampada Grameen Mahila Sanstha)

*Moderator:* Cynthia Eyakuze (OSI)

*Perspectives:* Brief discussion with representatives of affected communities on their experiences and perspectives related to HIV testing and counseling and human rights, followed by Q&A session.

**10:20 a.m. Policy and Practice**

**Case studies of HIV testing and counseling among pregnant women in South Africa and Ukraine**

## The Role of Human Rights in Ensuring Universal Access to HIV Testing and Counselling

*Panelists:* Allison Groves (University of North Carolina Gillings School of Global Public Health), South Africa; Halyna Skipalska (HealthRight International), Ukraine

*Moderator:* Miriam Sabin (WHO)

10:45 a.m. Break

**11:00 a.m. Policy scan and qualitative study of the 3 C's in PITC and barriers to PITC implementation**

*Panelist:* Maria Claudia Escobar (AIDSTAR)

*Moderator:* Miriam Sabin (WHO)

**11:15 a.m. Organizational Perspectives: Presentations by WHO, UNAIDS, and the Gates Foundation on their work relating to implementing human rights protections in HIV testing and counseling scale-up, followed by Q&A session.**

*Panelists:* Miriam Sabin (WHO), Jason Sigurdson (UNAIDS), Ray Yip (The Bill & Melinda Gates Foundation)

*Moderator:* Joe Amon (Human Rights Watch)

12:45 p.m. Lunch

**1:45 p.m. The Role of Human Rights in HIV Testing and Counseling Scale-Up**

*Facilitator:* Jonathan Cohen (OSI)

**1:55 p.m. Addressing Political and Systemic Barriers and Concerns**

*Panelists:* Anne Gathumbi (Open Society Initiative for East Africa) and Roger Staub (Federal Office of Public Health, Switzerland)

*Facilitator:* Jonathan Cohen (OSI)

Quick framing presentations to outline the key political and systemic barriers

**2:15 p.m. Plenary discussion on political and system barriers and concerns**

*Facilitator:* Josh Mintz

**2:45 p.m. Small group discussions** (tables of approximately 8 people each)

To prioritize the top three barriers to the protection of human rights or human rights concerns and then identify two to three *specific and concrete actions* that will be taken to address each barrier or concern and suggest ways to measure progress towards reducing these barriers over time

4:00 p.m. Break

**4:15 p.m. Plenary discussion: Reports from the small group discussions**

*Facilitator:* Josh Mintz

Reports on discussions and consensus on key barriers, concerns and priority action items leading to measurement of progress over time

**5:45 p.m. Close**

7:00 p.m. Group dinner at the Carlights restaurant at the hotel

## Tuesday, October 13, 2009

### 9:00 a.m. Addressing Technical Barriers and Concerns

*Panelists:* Sofia Gruskin (Harvard School of Public Health) and Donna Leigh Higgins (Consultant)

*Facilitator:* Josh Mintz

Quick framing presentations to outline the key technical barriers to implementing human rights protections and potential tools that can be developed and disseminated to facilitate implementation of human rights protections

### 9:15 a.m. Plenary discussion on technical barriers and concerns

*Facilitator:* Josh Mintz

10:00 a.m. Break

### 10:15 a.m. Addressing Technical Barriers and Concerns, cont.

*Panelists:* Suzanne Maman (University of North Carolina Gillings School of Global

Public Health), Meena Seshu (Sampada Grameen Mahila Sanstha), Paul Wekesa (Liverpool VCT Care & Treatment)

*Facilitator:* Susan Timberlake (UNAIDS)

### 11:30 a.m. Small group discussions (tables of approximately 8 people each)

To prioritize the top three barriers to the protection of human rights or human rights concerns and then to identify two to three *specific and concrete actions* that will be taken to address each barrier or concern and suggest ways to measure progress towards reducing these barriers over time

12:30 p.m. Lunch

### 1:30 p.m. Moving Forward / Action Planning

- Report back from small group discussions
- Address unresolved issues from the previous sessions
- Identify a plan for WHO, UNAIDS, national government, and human rights organizations to continue collaborating on HIV testing and counseling programmes
- Develop an Action Plan for moving the work forward (clarity on next steps, responsibilities, timelines, etc.)

3:00 p.m. Break

### 3:15 p.m. Continue discussions

See 1:30 p.m. description

### 4:30 p.m. Next Steps and Closing Comments

### 5:00 p.m. Close

7:00 p.m. Group dinner at the Carlights restaurant at the hotel

## PARTICIPANT LIST

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**Joe Amon**

Director of Health & Human Rights Division  
Human Rights Watch  
[amonj@hrw.org](mailto:amonj@hrw.org)

**Ron Bayer**

Professor, Center for the History & Ethics of Public Health  
Columbia University, Mailman School of Public Health  
[rb8@mail.cumc.columbia.edu](mailto:rb8@mail.cumc.columbia.edu)

**Jenny Bell**

Manager  
Justice & Women  
[jaw@futurenet.co.za](mailto:jaw@futurenet.co.za)

**Michaela Clayton**

Director  
AIDS and Rights Alliance for Southern Africa (ARASA)  
[michaela@arasa.org.na](mailto:michaela@arasa.org.na)

**Jonathan Cohen**

Project Director, Law & Health Initiative  
Open Society Institute  
[jcohen@sorosny.org](mailto:jcohen@sorosny.org)

**Joanne Csete**

Associate Professor, Population & Family Health  
Columbia University, Mailman School of Public Health  
[jc1188@columbia.edu](mailto:jc1188@columbia.edu)

**Delme Cupido**

APM, HIV Program: Policy & Law  
Open Society Initiative for Southern Africa  
[delmec@osisa.org](mailto:delmec@osisa.org)

**Vivek Divan**

Consultant, Bureau for Development Policy, HIV/AIDS Group  
United Nations Development Program  
[vivekdivan@gmail.com](mailto:vivekdivan@gmail.com)

**Vicki Doyle**

QI Consultant  
Independent  
[vpdoyle@aol.com](mailto:vpdoyle@aol.com)

**Maria Escobar**

HIV CT Officer  
AIDSTAR One  
[maria\\_escobar@jsi.com](mailto:maria_escobar@jsi.com)

**Cynthia Eyakuze**

Project Director, Public Health Watch  
Open Society Institute  
[ceyakuze@sorosny.org](mailto:ceyakuze@sorosny.org)

**Tamar Ezer**

Program Officer, Law & Health Initiative  
Open Society Institute  
[tezer@sorosny.org](mailto:tezer@sorosny.org)

**Thato Farirai**

Counseling & Testing Specialist  
Centers for Disease Control & Prevention's Global AIDS Program- South Africa  
[farirait@sa.cdc.gov](mailto:farirait@sa.cdc.gov)

**Loon Gangte**

President  
Delhi Network of Positive People  
[loon\\_gangte@yahoo.com](mailto:loon_gangte@yahoo.com)

**Anne Gathumbi**

Program Manager, Health & Rights  
Open Society Initiative for East Africa  
[agathumbi@osica.org](mailto:agathumbi@osica.org)

**Françoise Girard**

Director, Public Health Program  
Open Society Institute  
[fgirard@sorosny.org](mailto:fgirard@sorosny.org)

**Allison Groves**

Research Associate  
Department of Health Behavior & Health Education  
University of North Carolina at Chapel Hill, Gillings School of Global Public Health  
[grovesa@email.unc.edu](mailto:grovesa@email.unc.edu)

**Sofia Gruskin**

Director, Program on International Health & Human Rights  
Professor, Health & Human Rights  
Harvard School of Public Health  
[sgruskin@hsph.harvard.edu](mailto:sgruskin@hsph.harvard.edu)

**Lydia Guterman**

Program Coordinator, Public Health Program  
Open Society Institute  
[lguterman@sorosny.org](mailto:lguterman@sorosny.org)

**D. Leigh Higgins**

Public Health Consultant  
[dlh0514@yahoo.com](mailto:dlh0514@yahoo.com)

**Ralf Jürgens**

Consultant- HIV/AIDS, Health, Policy & Human Rights  
[rjurgens@sympatico.ca](mailto:rjurgens@sympatico.ca)

**Ying-Ru Lo**

Unit Coordinator, Prevention in the Health Sector, HIV Department  
World Health Organization  
[loy@who.int](mailto:loy@who.int)

**Suzanne Maman**

Assistant Professor, Department of Health Behavior & Health Education  
University of North Carolina at Chapel Hill, Gillings School of Global Public  
Health  
[maman@email.unc.edu](mailto:maman@email.unc.edu)

**Joshua Mintz**

Partner  
Cavanaugh, Hagan, Pierson & Mintz  
[jmintz@consultchpm.com](mailto:jmintz@consultchpm.com)

**Promise Mthembu**

Senior Project Coordinator, HIV Management Cluster  
Reproductive Health HIV Research Unit  
[pamthembu@rhru.co.za](mailto:pamthembu@rhru.co.za)

**Christine Munduru**

Health & Human Rights Program Officer  
Open Society Initiative for East Africa  
[cmunduru@osica.org](mailto:cmunduru@osica.org)

**Carla Obermeyer**

Scientist, Surveillance & Implementation Research/HIV Department  
World Health Organization  
[obermeyerc@who.int](mailto:obermeyerc@who.int)

**Rosemary Okello-Orlale**

Executive Director  
African Woman & Child Feature Service  
[rookello@awcfs.org](mailto:rookello@awcfs.org)

**Amolo Okero**

Technical Advisor, HIV Department  
World Health Organization

**Eunice Oyiela**

KEMRI-Wellcome Trust Research Program  
HTC  
[eoyiela@kilifi.kemri-wellcome.org](mailto:eoyiela@kilifi.kemri-wellcome.org)

**Andreas Reis**

Department of Ethics, Equity, Trade & Human Rights  
World Health Organization  
[reisa@who.int](mailto:reisa@who.int)

**Mila Rosenthal**

Executive Director  
HealthRight International  
[mila.rosenthal@healthright.org](mailto:mila.rosenthal@healthright.org)

**Miriam Sabin**

Scientist, HIV Department  
World Health Organization  
[sabinm@who.int](mailto:sabinm@who.int)

**Andy Seale**

Senior Advisor, Gender: Sexual & Gender Diversity  
Global Fund to Fight AIDS, Tuberculosis and Malaria  
[Andy.Seale@theglobalfund.org](mailto:Andy.Seale@theglobalfund.org)

**Meena Seshu**

Secretary General  
Sampada Grameen Mahila Sanstha (SANGRAM)  
[meenaseshu@yahoo.com](mailto:meenaseshu@yahoo.com)

**Jason Sigurdson**

Human Rights & Law Programme Officer  
Joint United Nations Programme on HIV/AIDS  
[sigurdsonj@unaids.org](mailto:sigurdsonj@unaids.org)

**Tin Tin Sint**

Medical Officer- MTCT  
Department of HIV/AIDS  
HIV/AIDS, TB & Malaria Cluster  
World Health Organization  
[sintt@who.int](mailto:sintt@who.int)

**Halyna Skipalska**

Ukraine Country Director  
HealthRight International  
[halyna.skipalska@healthright.org](mailto:halyna.skipalska@healthright.org)

**Roger Staub**

Head of AIDS Unit  
Federal Office of Public Health, Switzerland  
[roger.staub@bag.admin.ch](mailto:roger.staub@bag.admin.ch)



**Susan Timberlake**

Senior Adviser, Human Rights & Law  
Joint United Nations Programme on HIV/AIDS  
[timberlakes@unaids.org](mailto:timberlakes@unaids.org)

**Mary Ann Torres**

Senior Policy Advisor  
International Counsel of AIDS Service Organizations (ICASO)  
[maryannt@icaso.org](mailto:maryannt@icaso.org)

**Viktoriya Tymoshevskya**

Public Health Initiatives Program Director  
International Renaissance Foundation (IRF)  
[tymoshevskya@irf.kiev.ua](mailto:tymoshevskya@irf.kiev.ua)

**Francois Venter**

Clinical Director  
Reproductive Health & HIV Research Unit  
University of the Witwatersrand, South Africa  
[fventer@rhru.co.za](mailto:fventer@rhru.co.za)

**Paul Wekesa**

Director of Services  
Liverpool VCT Care & Treatment  
[pwekesa@liverpoolvct.org](mailto:pwekesa@liverpoolvct.org)

**Ray Yip**

Country Director, China  
Bill & Melinda Gates Foundation  
[ray.yip@gatesfoundation.org](mailto:ray.yip@gatesfoundation.org)

## Ten human rights elements of the UNAIDS/WHO *Guidance on Provider-Initiated HIV Testing and Counseling in Health Facilities* (2007)<sup>2</sup>

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

Element/Standard	UNAIDS/WHO <i>Guidance</i>
<p><b>1. Right to Health</b> (Availability, Accessibility, Acceptability, Quality)</p> <p><i>ICESCR article 12 – right to the highest attainable standard of health</i></p>	<p>In all types of HIV epidemics, health care providers should recommend HIV testing and counselling as part of the standard of care to: all adults, adolescents or children who present to health facilities with signs, symptoms or medical conditions that could indicate HIV infection.</p> <p>In generalized epidemics where an enabling environment is in place and adequate resources are available, including a recommended package of HIV prevention, treatment and care, health care providers should recommend HIV testing and counselling to all adults and adolescents seen in all health facilities.</p> <p>Strategies are needed to increase access to and uptake of HIV testing and counselling for [marginalized groups on concentrated epidemics], particularly through innovative client-initiated approaches such as services delivered through mobile clinics, in other community settings, through harm reduction programmes or through other types of outreach. Prisoners should be able to access client-initiated HIV testing and counselling at any time during incarceration without being subject to mandatory HIV testing.</p> <p>Regular evaluations of health care provider performance and patient satisfaction (including testing processes, pre-test information, consent process and post-test counselling) can help improve the effectiveness, acceptability and quality of HIV testing and counseling services.</p> <p>Resource and capacity constraints may require a phased implementation of provider-initiated HIV testing and counselling.</p>
<p><b>2. Consent</b></p> <p><i>ICCPR article 9 – right to security of the person</i></p> <p><i>ICESCR article 12 – right to the highest attainable standard of health</i></p>	<p>Individuals must specifically decline the HIV test if they do not want it to be performed.</p> <p>Concerns about the potential coercion of patients and adverse outcomes of disclosure underscore the importance of adequate training and supervision for health care providers and the need for close monitoring and evaluation of provider-initiated HIV testing and counselling programmes.</p> <p>Endorsement of provider-initiated HIV testing and counselling by WHO and UNAIDS is not an endorsement of coercive or mandatory HIV testing. WHO and UNAIDS do not support mandatory or compulsory testing of individuals on public health grounds.</p>

<sup>2</sup> This table was prepared by Jonathan Cohen for the OSI/UNAIDS/WHO convening, “The Role of Human Rights in Ensuring Universal Access to HIV Testing and Counseling,” Geneva, October 12-13, 2009.

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	<p>Governments may also need to develop and implement clear legal and policy frameworks that stipulate 1) the specific age and/or circumstances in which minors may consent to HIV testing for themselves or for others, and 2) how the assent of and consent for adolescents should best be assessed and obtained.</p> <p>Guidance and ongoing supervision must be provided to health care providers on the process of obtaining informed consent. Patients must receive adequate information on which to base a personal and voluntary decision whether or not to consent to the test, and be given an explicit opportunity to decline a recommendation of HIV testing and counselling without coercion. More detailed guidance on the process of obtaining informed consent appears in Section 6.</p>
<p><b>3. Confidentiality</b></p> <p><i>ICCPR article 17 – right to privacy</i></p> <p><i>ICESCR article 12 – right to the highest attainable standard of health</i></p>	<p>Because UNAIDS and WHO encourage voluntary disclosure of HIV status and ethical partner notification and counselling, national policies and ethical codes should also be developed to authorize partner notification in clearly defined circumstances.</p> <p>Training must emphasize that health care providers have a responsibility to maintain the confidentiality of HIV test results. The fact that the patient has provided informed and voluntary consent to an HIV test, and the test result, should be documented in patient records. Clinical care can be undermined by not recording HIV results or not communicating results to other health care providers responsible for patient care. Medical records, including test results, should only be shared with health care professionals who have a direct role in the ongoing management of the patient. These principles apply to both verbal and written communications. Patients should be offered advice on the safe-keeping of patient-held records, such as antenatal care (ANC) cards and child health cards.</p> <p>UNAIDS and WHO encourage voluntary disclosure of HIV status and ethical partner notification and counselling. This may require national policies and public health legislation authorizing partner notification in clearly defined circumstances, as well as the promotion of professional ethical codes among health care and social service providers. While beyond the scope of this document, these issues are comprehensively addressed in the UNAIDS/WHO publication <i>Opening up the HIV/AIDS epidemic: Guidance on encouraging beneficial disclosure, ethical partner counselling &amp; appropriate use of HIV case-reporting</i>.</p>
<p><b>4. Privacy</b></p> <p><i>ICCPR article 17 – right to privacy</i></p> <p><i>ICESCR article 12 – right to the highest attainable standard of health</i></p>	<p>Privacy must also be ensured. For example, informed consent should be sought and given in a private setting and post-test counselling for an HIV-positive patient and other communications relating to HIV status should take place away from other patients or staff not involved with that patient's care. Medical records administrators may need to receive specific training in the appropriate handling of medical records in clinical settings where HIV testing and counselling is performed.</p>
<p><b>5. Pre- and post-test counseling</b></p>	<p>Depending on local conditions, pre-test information can be provided in the form of individual information sessions or in group health information talks. Informed consent should always be given individually, in private, in the presence of a health care</p>

<p><i>ICCPR article 9 – right to security of the person</i></p> <p><i>ICCPR article 19 – right to information</i></p> <p><i>ICESCR article 12 – right to the highest attainable standard of health</i></p>	<p>provider. When recommending HIV testing and counselling to a patient, the health care provider should at a minimum provide the patient with the following information...</p> <p>Post-test counselling is an integral component of the HIV testing process. All individuals undergoing HIV testing must be counselled when their test results are given, regardless of the test result. Counselling for those whose test result is <i>HIV-negative</i> should include the following minimum information...</p>
<p><b>6. Non-discrimination</b></p> <p><i>ICCPR article 26 – right to equality</i></p> <p><i>ICESCR article 12 – right to the highest attainable standard of health</i></p>	<p>Optimal delivery of provider-initiated HIV testing and counselling in the long term requires that laws and policies against discrimination on the basis of HIV status, risk behaviour and gender are in place, monitored and enforced.</p> <p>Declining an HIV test should not result in reduced quality or denial of services that do not depend on knowledge of HIV status.</p> <p>People living with or who are suspected of having HIV frequently report mistreatment or discrimination on the part of health care providers. The implementation of provider-initiated HIV testing and counselling provides an opportunity to raise awareness about HIV/AIDS and human rights issues among health care providers and administrators and reinforce their adherence to appropriate standards of practice. Staff interacting with patients should receive specific training and ongoing supervision to address the needs of people living with and at-risk for HIV. It should be standard practice to treat all patients decently, with respect and without discrimination on the basis of HIV status or risk behaviours, and to help patients address potential negative social consequences of HIV testing. Involving people living with HIV, members of at-risk populations and their advocates in training sessions for health care providers on these issues is strongly recommended.</p> <p>Optimal delivery of provider-initiated HIV testing and counselling in the long term requires that laws and policies against discrimination on the basis of HIV status, risk behaviour and gender are in place, monitored and enforced. These include legal and social protections which enhance privacy, autonomy and gender equality. Implementing these broad social and legal protections is the responsibility of diverse stakeholders, including parliamentarians, ministries of the interior, health and justice and civil society groups, emphasizing the need for multisectoral commitment to scaling up provider-initiated HIV testing and counselling.</p>
<p><b>7. Links to services</b></p> <p><i>ICCPR article 4 – non-derogation from rights unless strictly required</i></p> <p><i>ICESCR article 12 – right to the highest attainable standard of</i></p>	<p>Provider-initiated HIV testing and counselling should be accompanied by the recommended package of HIV-related prevention, treatment, care and support services shown in Table 1. Although not all the services need necessarily be available in the same facility as where the HIV test is performed, they should be available through local referral.</p> <p>Although access to antiretroviral therapy is expanding, in many settings it is not yet available. The package of care and support services described in Table 1 may nevertheless provide significant health benefits for people who are diagnosed HIV-</p>

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<p><i>health</i></p>	<p>positive. Although access to antiretroviral therapy should not be an absolute prerequisite for the implementation of provider-initiated HIV testing and counselling, there should at least be a reasonable expectation that it will become available within the framework of a national plan to achieve universal access to antiretroviral therapy for all who need it.</p> <p>Antiretroviral prophylaxis and infant feeding counselling are important interventions for the prevention of mother-to-child transmission. These interventions must be available as part of the standard of care for pregnant women who are diagnosed HIV-positive through provider-initiated HIV testing and counselling.</p> <p>Provision of extensive prevention services may not be feasible or required for all people who test HIV-negative in many resource-limited health facilities. However, in most cases, these can be made available through referral to community-based or other appropriate services.</p> <p>Health care providers will require training on the referral needs of patients, their partners and family members and the services that are available locally to provide follow-up and support, including the availability of client-initiated HIV testing and counselling services.</p>
<p><b>8. Protection from harm</b></p> <p><i>ICCPR article 4 – non-derogation from rights unless strictly required</i></p> <p><i>ICCPR article 9 – right to security of the person</i></p> <p><i>ICESCR article 12 – right to the highest attainable standard of health</i></p>	<p>Adaptation of this guidance at country level will require an assessment of the local epidemiology as well as the risks and benefits of provider-initiated HIV testing and counselling, including an appraisal of available resources, prevailing standards of HIV prevention, treatment, care and support, and the adequacy of social and legal protections available.</p> <p>Where there are high levels of stigma and discrimination and/or low capacity of health care providers to implement provider-initiated HIV testing and counselling under the conditions of informed consent, confidentiality and counselling, adequate resources should be devoted to addressing these issues prior to implementation. Decisions around implementation should be made in consultation with all relevant stakeholders, including civil society groups and people living with HIV/AIDS.</p> <p>At the same time as provider-initiated HIV testing and counselling is implemented, equal efforts must be made to ensure that a supportive social, policy and legal framework is in place to maximize positive outcomes and minimize potential harms to patients. This includes: community preparedness and social mobilization; adequate resources and infrastructure; health care provider training; health care provider codes of conduct and methods of redress for patients; and a strong monitoring and evaluation system.</p> <p>Populations most at-risk of HIV transmission may be more susceptible to coercion, discrimination, violence, abandonment, incarceration or other negative consequences upon disclosure of an HIV-positive test result. Health care providers will usually require special training and supervision to uphold standards of informed consent and confidentiality for these populations. Additional discussion of the right to decline HIV testing, of the risks and benefits of HIV testing and disclosure, and about social support needs may be required. An “opt-in” approach to informed consent may merit consideration for highly vulnerable populations.</p> <p>Women may be more likely than men to experience discrimination, violence,</p>

	abandonment or ostracism when their HIV status becomes known.
<p><b>9. Participation</b></p> <p><i>ICESCR article 12 – right to the highest attainable standard of health</i></p>	<p>Implementation of provider-initiated HIV testing and counselling should be undertaken in consultation with key stakeholders, including civil society groups and people living with HIV/AIDS.</p> <p>Involving most-at-risk populations and their advocates in the development of HIV testing and counselling protocols and in the monitoring and evaluation of provider-initiated HIV testing and counselling programmes will help to ensure that the most appropriate and acceptable practices are followed.</p>
<p><b>10. Redress</b></p> <p><i>ICCPR article 2(3) – right to a remedy</i></p> <p><i>ICESCR article 12 – right to the highest attainable standard of health</i></p>	<p>Health facilities should develop codes of conduct for health care providers and methods of redress for patients whose rights are infringed. Consideration should be given to the appointment of an independent ombudsman or patient advocate to whom breaches of HIV testing and counselling protocols and codes of conduct can be reported.</p>

UNAIDS, the Joint United Nations Programme on HIV/AIDS, is an innovative United Nations partnership that leads and inspires the world in achieving universal access to HIV prevention, treatment, care and support. Learn more at [unaids.org](http://unaids.org).



UNAIDS  
20 AVENUE APPIA  
CH-1211 GENEVA 27  
SWITZERLAND

Tel.: (+41) 22 791 36 66  
Fax: (+41) 22 791 48 35

[www.unaids.org](http://www.unaids.org)

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