



UNAIDS Global Reference Group on HIV/AIDS and Human Rights

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Issue Paper

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Review of Human Rights Implications of HIV Testing in Identified Purposes and Settings

Defining the Issue

As stated in Session 1, a systematic consideration of HIV testing from a human rights perspective would need to examine in the first instance if the *purpose* of the HIV test is consistent with the promotion and protection of human rights. If this is the case, then attention must be given to whether any restrictions or limitations on rights which occur through the *practice* of HIV testing are justifiable, and finally whether and how human rights are impacted through the actions taken when an individual has a positive test result. In an effort to begin to raise some of the newer issues inherent in each of these elements of testing below we attempt to look rather crudely at different components of the framework in more detail. Please refer also to the attached document which, while also rough, it is hoped can serve as a visual aid to our discussions.

Although the purpose of testing is key to our analysis, it is imperative that each purpose is addressed with attention to the specificities of practice and the implications of a positive test result. The key rights at issue would seem to be the right to health, to seek, receive and impart information, privacy, security of the person and non-discrimination. Other rights such as association and participation would of course be implicated but are not those primarily at issue. The determination of whether rights are being sufficiently respected, protected and fulfilled, including whether the public health gains may be sufficient to justify limitations of human rights in any of the circumstances described below requires a focus on the perceived and actual health or social benefits of the chosen approach to HIV testing, the strength of the evidence on which the decision is made, and the implications of a chosen testing strategy for particular individuals or populations, in specified locations and at particular points in time.

I The Purpose of the HIV Test

People voluntarily want to know their HIV status Testing for this purpose is strictly voluntary and confidential. Informed consent and pre and post test counseling remain key. Individuals can seek HIV testing simply because they want to know their status, following a partner's testing, after accidental occupational exposure, and fearing potentially unsafe sexual encounters particularly sexual assault. Some of the issues that arise include certain groups (e.g. young people) not being recognized as able to consent to access testing services even if they are offered; certain groups being pressured to undergo VCT (e.g. women by partners, employees by employers); services may be costly to the client, or if they are free are sufficiently burdened that shortcuts are taken (e.g. lack of trained personnel, cutting out pre-test counseling); and testing may not be linked to care services.

As part of routine health screening The largest issue here for discussion is the ways in which HIV testing in clinical care settings (e.g., primary care clinics, hospitals or private clinician's offices) is being made routine, and what specifically this means in relation to the testing process itself. Testing is either routinely imposed or offered. Informed consent is sometimes argued to be implicit, the argument being that the patient presents "voluntarily," and pre-counseling does not exceed the usual information procedures. Whether or not this is adequate is unclear. If HIV testing is integrated into a package of routine services in clinical care settings, the steps needed to ensure that rights are sufficiently considered throughout every stage of the testing process should be considered. In addition, when an individual presents at a clinical care setting, he or she has not necessarily made a decision to receive an HIV test, and may have presented for an entirely unrelated health concern. Further issues are raised around how testing for this purpose impacts quality of care, and whether testing is linked to access to care and treatment.

Precondition to access HIV/AIDS-related care and support, and/or treatment

Similarly at issue here is whether a test is offered or imposed and whether this is to diagnose a suspected infection based on an individual's symptoms, their behaviours, or in fact to link individuals to prevention, and care and support services. In some instances, HIV testing is mandated to access HIV related ART, but not other forms of HIV related care and treatment such as those applicable to some opportunistic infections. Attention also has to be given to whether ARTs are then made available to all that have a positive test result. At times, there is no law and policy direction from the State but protocols are instituted by the services themselves.

To reduce mother-to-child transmission The effectiveness of therapies to prevent MTCT has created an impetus to scale up HIV testing of pregnant women. When testing of pregnant women occurs during scheduled prenatal testing the issues to be considered include the issues raised above, but additionally the extent to which the service offered is to prevent MTCT, and the extent to which testing is being offered/provided to also ensure the woman herself can access needed care and support. The issues that arise when women are offered/provided the test during labor raises additional unique issues, due not only to gender-related vulnerabilities but to the additional vulnerabilities that may arise in relation to assuring consent (voluntary or otherwise) to an HIV test, the ways in which counseling (pre and post will be provided) including how and when a woman will be informed of a positive test result, what personal and social impact this may have, and how confidentiality of the test result will be protected. Links to access to services for both mother and child also have to be addressed. In the context of preventing MTCT, questions may arise also as to whether and, if so, how to involve male partners in the testing process as well.

Because of societal attitudes and prejudices towards certain individuals and population groups

Testing of people on the basis of societal attitudes and prejudices continues to fly in the face of human rights protections. The issues at stake have not changed over the years, including what efforts are made to ensure the confidentiality of test results. Established linkages do, however, exist between vulnerability to HIV infection and discrimination against certain populations and individuals. If care and treatment were available on demand, stigma and discrimination reduced, the testing voluntary, and means of redress of possible abuses available and applicable, despite societal attitudes and prejudices, the opportunity for early diagnosis among asymptomatic individuals might contribute to the "normalization" of HIV/AIDS, a trend being observed in the case of cancers in the

advent of therapy and cure.

To determine eligibility of individuals for activities, services, and goods The language of “routine” is particularly worrisome as it applies here. “Routine testing” as it is being discussed in relation to clinical care settings is increasingly creeping into discussions about testing for access to activities, services and goods such as university entrance, the eligibility for health and life insurance, and recent debates over testing of military personnel to determine their fitness to serve.

To donate blood or organs The purpose here remains to screen blood and organ donors for HIV infection to avoid transmission. The issues here have not changed relating to whether the blood/organ is being tested or the person, as well as whether communication of results to the donor occurs.

To collect and analyze information needed for epidemiological surveillance This testing is anonymous and unlinked and could be with or without the collection of demographic, social and behavioral data. An issue here is the degree to which such information may be used to identify and stigmatize individuals or communities on the basis of their social, behavioral, or other characteristics.

For research purposes Testing for research is usually voluntary and confidential and guided by norms of research ethics. The issues above would be relevant here.

II The Practice of the HIV Test

Testing Site and Location Testing may occur in health care settings, such as primary care clinics, hospitals, offices of clinicians, and specialized clinics (e.g. antenatal care, family planning, STI treatment, substance abuse treatment). In these locations, testing may be routinely imposed (with or without informed consent or right of dissent) or routinely offered (with or without consequences of dissent). It may be integrated into existing health services, or exist at stand-alone facilities or temporary mobile/outreach facilities. Testing, however, also occurs in non-health care settings such as at home, at the workplace, police stations, prisons, universities, immigration offices, and the armed services. Each raises particular issues for consideration.

Population Being Tested Testing may be voluntarily accessible to the population as a whole or there may be legal, policy or community norms which limit the access of certain members of the population such as on the basis of age and gender. Testing can be targeted at TB patients, pregnant women, STI patients, MSM, IDUs, sex workers, prisoners, military, immigrants, travelers (cross national borders), and/or other populations stigmatized or discriminated against within a particular society. Each of these populations may be subjected to specific requirements and practices in relation to the testing process itself, as well as specifically in relation to informed consent, confidentiality and health and social consequences. These issues must be considered in development or implementation of any HIV testing policy.

The Components of the Testing Process There is general agreement that HIV testing should include the following components:

- client decision to access services that offer HIV testing and counseling;
- pre-test counseling (information and/or counseling provided to client regarding HIV testing and the implications and likely outcomes based on the result of the test);
- voluntary decision of client to be tested or not tested;

- testing;
- return of client to receive results (not necessary for rapid testing);
- provision of results to client; and
- post-test counseling and support (provision of post-test information, counseling, and/or referral).

III The Implications of a Positive HIV Test

An HIV test is a crucial step for those that test positive to access prevention, care, support, and treatment services. However, a critical aspect of HIV testing with significant implications for the promotion and protection of human rights is what happens with a positive test result. Attention must be given to whether and how positive results are conveyed to care providers or disclosed to partners, family members, employers, the state (with a name attached/without a name but an identifier of some kind), what actor has responsibility for doing this, and whether this is done in person, by letter, by registry or some other modality. Within any of the new expanded models for testing now under discussion, how, to whom and for what purpose results are given has to be carefully addressed.

Supporting Documents

- 1) Chart on Elements of HIV Testing, by Reference Group Secretariat.

This Issue Paper was prepared by the Reference Group Secretariat to facilitate discussion at the Reference Group's August 2003 meeting.

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