



UNAIDS Global Reference Group on HIV/AIDS and Human Rights

Third Meeting, Geneva, 28-30 January 2004

Issue Paper

Status: final

The policy and programmatic implications of a positive test result. Some preliminary considerations

Defining the Issue

The fact that an HIV test is a crucial step for those that test positive to access prevention, care, support, and treatment services is undisputed. However, as policies are responding to the need to scale up HIV testing, there is little discussion about the ways in which these policies should consider how positive test results are conveyed, to whom and for what reasons, areas which require consideration in any scale up efforts.

Public health laws, such as those that address sexually transmissible and communicable diseases may govern HIV testing and disclosure, in the absence of explicit direction from HIV specific laws or directions within a national AIDS plan. In lieu of laws and policies, it is important to consider how ordinary practice within health care settings may also influence how and to whom communication of private health information is made. This issue paper begins to consider some implications of HIV testing in the context of individual diagnostics. In this context, test results may be conveyed for purposes of accessing treatment and services, and in relation to reporting and disclosure in a variety of forms. This paper does not explore these issues as linked to implications of testing for epidemiological purposes, for example, through anonymous-unlinked methods implemented at antenatal clinics and other sentinel sites.

Manner of disclosure: how individuals learn about their HIV test result

Testing policies are generally silent as to how the results of HIV tests are to be communicated to the individual tested. Laws tend not to include this level of detail either. This leaves an unbounded field of discretion for health care workers. A few testing policies state that a trained health care professional or HIV counselor should communicate an individual's test results in person; communication by post or via telephone is discouraged. In the absence of clear guidelines, and consequences for breaching them, it has been common practice for individuals to be notified by post, or in some settings, through a message left at a person's home.

The circumstances of HIV testing may influence the manner of disclosure, as well as access to appropriate care, treatment, and services. For example, pregnant women in labor may be tested for HIV. In addition to the obvious concerns regarding consent, the testing policy, may also fail to specify when the test results are communicated: during the birth? Immediately afterward? In the context of being told the child's status? Such policies also may not consider the links between a positive test result and how these women are to access care and treatment if it is available. One hopes that in free standing VCT clinics testing policies and protocols may be

more elaborated, and that this is likely to facilitate confidential disclosure of test results and referral to appropriate care and treatment but this is not certain.

Disclosure and Reporting: who else can learn the results of a positive HIV test

Most national AIDS policies which consider these issues incorporate general principles of medical ethics: that all medical information, including HIV status, be kept in confidence, and disclosed to the individual only, and to others if at all, only after permission of that individual is obtained. Such policies are sometimes translated into law (the breach of which may give rise to some form of redress). For example, South Africa's HIV/AIDS policy guidelines state that "The information regarding the result of the test must remain fully confidential, and may be disclosed in the absence of an *overriding legal or ethical duty* only with the individual's fully informed consent."ⁱⁱ Botswana's proposed National AIDS policy is also predicated on medical information being held in strict confidence.

Nonetheless, national level policies consider very different types of things to be "overriding" exceptions, justifying test results being given to others. Test results will be disclosed for a range of reasons to **third parties**, including in order to access treatment. These include:

- **Selected health care workers**ⁱⁱ: a) to provide necessary care and treatment to an HIV infected individual b) to enable health care workers to protect themselves from HIV exposure.ⁱⁱⁱ
- **Parents or Legal Guardians**: a) Where children are legally deemed unable to consent to an HIV test in the first place, b) where it is legally or culturally expected that the results be shared with parents/legal guardians in order to, for example access treatment.
- **Public Health Authorities**: a) as part of public health laws that specify a range of communicable and sexually transmissible diseases that must be reported to the state authorities. At times confidentiality is preserved through a system of unique identifiers, general identifiers, or is "waived" by named reporting.
- **Partners**: Some public health laws provide discretion for health care professionals to notify an HIV infected person's partners provided certain procedures are followed: that the infected person received counseling, refused to consent to partner notification, the risk to the partner is real, there is advance notice of the disclosure, and follow up counseling is provided.^{iv}
- **Other institutions**: Some policies, either tacitly or expressly, permit test results to be shared with institutions for a variety of purposes, such as university entrance, insurance coverage, employment, etc.^v.
- **Contact tracing**: to trace the transmission path and contact potentially infected individuals.^{vi} Its public health rationale has been principally stated as towards prevention and promoting safer sexual practices; with the availability of ARVs, contact tracing has at times been defended as helping to ensure that infected people get treatment^{vii}.
- **Mandatory Named Reporting**: can occur without obtaining permission of the person tested, and be authorized by laws specific to HIV or to other diseases more generally. Health care workers may be required to report the name of

the HIV infected person to public health and/or other authorities. Policies vary as to whom, including specification of which governmental agencies, the results will be disclosed.

Access to Prevention, Care, Treatment, and Support Services: how individuals learn of available care, treatment and support services

Many testing policies require post-test counseling to refer HIV infected individuals to appropriate health care, treatment and support services, such as the US CDC guidelines. Policies may facilitate access to such services, or they may inadvertently erect barriers. As testing policies are revised to increase access to treatment, such explicit connections between test results and access to appropriate treatment must be set forth in as much detail as possible, with due regard to protecting the individual's rights to privacy. Testing policies are not often explicit about providing for a means of redress in the case of an unlawful or unethical breach of confidentiality.

Conclusion

As national HIV programs scale up for expanded access to treatment, laws, policies, and practices relating to testing will be crucial to the success or failure of the initiative. Gaps and silences in law and policy create much room for discretion, abuse, and lack of accountability. Laws and policies that set forth in some detail how test results are to be communicated, to whom, and for what purpose, have more potential for promoting and protecting the rights of infected individuals, as well as facilitating access to treatment.

This Issue Paper was prepared by Reference Group Secretariat to facilitate discussion for the Reference Group's January 2004 meeting.

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ⁱ See <http://www.cadre.org.za/BAC/BACpdf/HIV%20testing.pdf>

ⁱⁱ Most policies are silent on who is covered in the definition of health care worker or professional.

ⁱⁱⁱ National Policy on HIV/AIDS, <http://www.tanzania.go.tz/healthf.html>

^{iv} Id.

^v Outside the health care setting, other specific areas where testing and disclosure policies may be relevant include the military, immigration, state custodial situations, sexual assault, and other areas where knowledge by a third party of a person's HIV status is a pre-requisite to accessing goods or services. These situations are not discussed in this issue paper, because its focus is on the implications of a positive test result within health care settings.

^{vi} <http://odin.dep.no/archive/shdvedlegg/01/04/HIVAI068.pdf>

^{vii} Evidence indicates, however, that named reporting can cause a decrease in voluntary HIV testing, in contrast with several studies that show that the availability of anonymous testing services significantly increases the number of people being tested for HIV infection. When such named disclosure is not linked to care and services, there are additional human rights considerations: sharing information with partners and family could lead to violence and/or divorce, stigma and discrimination. In such cases, the state (both inside and outside of the health sector), public health workers, and "contacts," would receive information about the individual's HIV status.