GUIDELINES

HIV LEGAL AND ETHICAL ISSUES

Elsabé Klinck

Legal Advisor, South African Medical Association

A comprehensive set of Guidelines is available from the South African Medical Association at (021) 530-6528, or e-mail emacdonald@samedical.org. The Guidelines include all relevant legislation, ethical rules and policy documents pertaining to HIV/AIDS.

When dealing with HIV, doctors have to address a number of ethical and legislative requirements, or where they do not have the time or experience to provide, for example, comprehensive counselling, they must see to it that patients have undergone this. Many of the principles involved are no different from those applicable to testing for or treatment of any disease. However, the stigma attached to HIV and the politicisation of the pandemic have magnified the importance of doctors adhering to these rules. In terms of legislation, specific mention is made of HIV in certain laws, and doctors have to be aware of these.

A very important ethical principle that underpins doctors' conduct in dealing with the pandemic is that of patient advocacy. Patients often do not know that they have certain legislative protection. Ill-informed perceptions often underlie a refusal to be tested or a refusal to disclose HIV-positive status. Non-exhaustive checklists are provided in this article to guide doctors through the general processes.

Pre-test counselling forms part of the process of obtaining **informed consent.** By not addressing these aspects, a health care professional may be found not to have obtained *informed* consent.

The requirement to obtain informed consent before any test, treatment, diagnosis or intervention has been part of South African medical ethics and law since 1912. The human right of freedom and security of the person lends further support to this principle. It has two aspects: sufficient information, and an understanding of that information and its implication for the patient. The courts judge this from the perspective of the patient, and not from the perspective of the health care professional.

Post-test counselling has long been recognised as imperative, in view of the nature of the pandemic, the role that positive HIV status plays in continued health care decisions, and the necessity of behavioural changes following a positive (and negative!) test result.

PRE-TEST COUNSELLING	
The patient knows why an HIV test has to be done (e.g. insurance purposes, continued medical care, pregnancy, solving the 'puzzle' of recurring infections, etc.), and why knowing one's HIV status is important.	/
Opportunity is provided for the patient to express concern and uncertainty, and these concerns have been addressed.	1
The patient knows what an HIV test is and how it will be done.	1
The patient knows how long it will take before s/he will have the result.	1
The patient knows who the result will be provided to (e.g. his/her GP or the sister at the local clinic) and that s/he is responsible for getting those results from that health care professional.	
The patient has been prepared to think about what a positive or a negative result may mean for him or her, specifically in relation to continued health care and the reason why the test has been commissioned in the first place.	
The patient has been provided with sufficient opportunity to ask questions and to think about the possibility/necessity of a test.	1
The patient has been provided with details of where counselling and support services can be obtained.	1

TESTING FOR HIV (INFORMED CONSENT)	
The patient understands that an HIV test is to be performed and has indicated such understanding clearly, if necessary through the assistance of an interpreter.	1
The patient knows what the implications of the test might be, e.g. that insurance cover may be denied, or that a baby may be born HIV-positive, and/or that medication would have to be prescribed.	1
The patient has signed (or refused to sign) an informed consent form, indicating such understanding. In the case of a refusal, no tests may be performed.	1
 The informed consent form included: The full names and identity number of the patient. Reference to the person who informed the patient about the aspects found in the consent form. That the patient has been informed about the nature, conduct, benefits, risks and implications involved in undertaking an HIV test and/or treatment and/or intervention. That the patient has received information on HIV, the test and/or treatment and has had an opportunity to ask questions. That the patient has been provided with an opportunity to consider whether s/he wants the test to be performed. The patient freely and voluntarily agrees to the performance of the test/treatment/intervention. That the test concerns the drawing of a blood sample and the performance of an HIV antibody or HIV test on that sample. That the patient agrees to the utilisation of such a result in an anonymous format for purposes of research and/or data collection. That the results will remain confidential, unless the patient has provided informed consent to a disclosure. That the patient knows that s/he is at any stage free to withdraw such consent. 	
Where the patient is a child, that the provisions of the Child Care Act have been complied with (i.e. independent, informed consent for those 14 years of age and older for medical treatment).	1
Where the patient is mentally incapable of consenting, that relevant legislative requirements are net, e.g. the Mental Health Care Act.	1
hat the patient has provided the laboratory conducting the test with the name of a GP or health care facility to whom the results could be made available and who would be able to discuss future health care options with the patient.	1

The meaning of a positive or negative result has been discussed, including, depending on the type of test used, the possibility of a false-negative result.	
How a patient should protect him/herself against infection or reinfection and how s/he should protect others from getting infected, including, where applicable, the issue of breast-feeding.	1
Various treatment options (antiretroviral therapy (ART), post-exposure prophylaxis (PEP), treatment for opportunistic infections), effects and demands in terms of regularly taking medication and costs (including implications for medical scheme funding) have been discussed.	1
How HIV status will affect future medical care.	1
Dealing with the issue of possible disclosure to significant others, (potential) sex partners, family members, employers, other health care workers, etc.; as well as the obstacles and opportunities the patient sees in this regard.	1
Issues of religion, culture and beliefs that may influence the patient's choices and behaviour have been recognised and addressed in a positive and constructive manner.	1
Possible lifestyle changes and preparation for these.	1
Addressing issues such as death, surviving children and care or adoption, families, concerns about insurance and funeral policies, etc.	1
Where continued counselling is impossible for the particular health care worker, the patient has been referred to an appropriate counsellor or counselling facility.	1

Confidentiality as a cornerstone principle in medical ethics is found in a number of important sources, such as the HPCSA's ethical rules, the Promotion of Access to Information Act, the Bill of Rights in the South African Constitution, the regulations to the Medical Schemes Act and proposed legislation such as the National Health Bill.

Doctors are often faced with particular situations placing them in a difficult position, where they may experience a conflict between the requests made by third parties, and the interests of their patients. Health care professionals may unknowingly assist third parties in unlawfully obtaining an HIV test, for example. It is therefore imperative that health care professionals are knowledgeable about the basic legislative requirements applicable to these situations.

CONFIDENTIALITY The patient has been assured of the health care professional's duty to preserve confidentiality.	1
The patient has been informed if disclosure has to be made in terms of a consent form s/he has signed (e.g. with an insurance company) or a managed care agreement with the patient's medical practitioner in terms of the regulations to the Medical Schemes Act.	✓
The patient has been advised of the desirability of disclosure to sex partners and significant others and an offer has been made to assist the patient in such a disclosure.	1
If the medical practitioner intends to breach confidentiality, s/he is aware of and takes full responsibility for the legal and ethical implications of such a step. S/he should be convinced that there is an identifiable third party facing a real risk and the patient has been informed of the intended breach.	\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \
Where an employer or any third party has paid for the HIV test, no disclosure of the results of the test has been made to such employer or person, unless the patient has provided his/her informed consent for such a disclosure. The patient has been informed that s/he does not have to disclose to such entities or persons.	/
The patient's informed consent has been obtained for disclosures to subsequent health care professionals to whose treatment they have been referred, after issues such as the impact of HIV on postoperative care or health care treatment options have been explained.	/

LEGISLATIVE REQUIREMENTS

Occupational injuries and diseases:

- Health care professionals have been informed of the relevant protocols in their workplaces that deal with PEP after possible exposure to HIV.
- The source patient has not been tested without his/her informed consent.
- The health care professional has access to free testing, PEP and counselling.
- The employer has started proceedings under the Compensation of Occupational Injuries and Disease Act so as to ensure the payment of compensation to the health care professional.

Employment:

- The employer who has requested the HIV test has obtained a court order from the Labour Court authorising testing.
- The provisions set out in the court order have been complied with.
- No test results have been made available to the employer without the relevant employee's informed consent.
- Employees have not signed any document in which they waive their rights in terms of the Employment Equity Act of 1998
- Employees have been assured that there may be no discrimination based on their HIV status and no reduction in terms of employment benefits would take place.

Insurance:

- The patient/insured is aware of the exclusions found in his/her policy document.
- The patient is aware that Section 59 of the Long-term Insurance Act compels him/her to disclose all material medical facts at the time of applying for a policy.
- The patient is aware of the implications of the medical records consent form signed at the particular insurance company.
- The patient has been informed of specific HIV products offered by insurers.

Medical schemes:

- The patient knows the limits of his/her medical scheme benefits.
- The patient knows which treatment would be paid for as being part of the prescribed minimum benefits.
- The patient has considered the financial implications of HIV ART or treatment for opportunistic infections. The patient has reached a decision to either pay for it him/herself, seek participation in programmes that do provide ART and/or to apply for assistance at the medical scheme or other financing mechanism.
- The patient has been requested to provide the health care professional with clear instructions in terms of (non)disclosure to the scheme, particularly in the absence of a managed care agreement between the scheme and the health care provider.

Discrimination and patient empowerment:

- The patient knows that s/he may not be discriminated against and may challenge any decision pertaining to his/her health care, insurance, benefits, employment, etc. at an appropriate forum.
- Relief exists in the utilisation of the Promotion of Equality and Prevention of Unfair Discrimination Act, or by approaching NGOs or the Human Rights Commission, with particular complaints.