

HIV / AIDS
CURRENT LAW & POLICY

**Know your HIV Status:
Issues around HIV
Status**



Revised: Sept. 2002

KNOW YOUR HIV Status - Issues around HIV testing.

Why should you have an HIV test? What are the benefits of knowing your HIV status? What rules have to be followed by people who conduct HIV tests.

This pamphlet answers these and other questions.

CONTENTS

- 1 A brief summary of the rules for HIV testing
- 2 Introduction
- 3 The benefits of knowing your HIV status
- 4 ... and the risks
- 5 Common examples of violations
 - a When applying for a job
 - b At work
 - c When applying for medical aid
 - d In hospital, at clinics and when visiting your doctor
- 6 Insurance
- 7 Common law, legislation and policies
- 8 The law on HIV testing
 - a The common law rule on informed consent
 - b Legislation - The Constitution and the Bill of Rights
- 9 Policies on HIV testing
 - a Health Professions Council
Guidelines on the Management of Patients with HIV
Infection or AIDS

13	b	The National Policy on Testing for HIV	
	c	South African Medical Association "Human Rights and Ethical Guidelines on HIV: A Manual for Medical Practitioners"	
10		Enforcing your rights	15
		Glossary	16

What are HIV and AIDS?

HIV is the "Human Immunodeficiency Virus". It is the virus that eventually leads to AIDS.

AIDS is "Acquired Immune Deficiency Syndrome". Many people who have HIV eventually develop AIDS because the virus makes it difficult for their bodies to fight off diseases. It is not one sickness, but is a name given to many different illnesses, which people at this stage of the disease may get (such as TB and pneumonia).

It is **very important** to note that if you have HIV, it does **not** necessarily mean that you are sick. It sometimes takes years for someone who has HIV to develop AIDS. During this time, people who have HIV can lead normal and productive lives.

1 A brief summary of the rules for HIV testing

This booklet will look at all the current laws and policies that are in place dealing with HIV testing. They can be summarised as follows:

- An HIV test is a **medical procedure**.
- You must give your **informed consent** to a medical procedure.
- **Informed consent** means you must fully understand what the test is and what the consequences will be for you if you test positive or negative. To make sure you know this, you should be given counselling before the test. This is called "**pre-test counselling**".
- Pre-test counselling should give you enough information to properly decide whether or not you want to have the test.
- Once you have had counselling, you must be given time to decide what you want to do.
- If you decide **not** to have the test, no one can force you to.

If you decide to have the test, you must be given counselling when the results are given to you. This is called "**post-test counselling**".

2 Introduction

The decision on whether to have an HIV test, and when to do so, is **your decision** alone. Except in rare circumstances, you cannot be forced or required to take a test. Anyone who forces you to do so will both violate your rights and may be breaking the law.

It is possible to have HIV without even being aware of it. This is because HIV can live in the human body for many years before it causes any illnesses. The only way of finding out is to have an HIV test. These tests are performed at most health clinics or you could ask your doctor or health care worker.

The benefits of knowing your HIV status (whether you have HIV or not) are very likely to outweigh the risks. It is important that **all** people should think about going for an HIV test.

The window period

It can take up to 3 months after someone is infected with HIV for it to show up in an HIV anti-body test. This is because your body takes some time to develop anti-bodies to try to fight off the virus. An HIV test checks for the presence of these **HIV anti-bodies** in your blood and it might give a false negative result in this three-month period (the tests are called ELISA or Western Blot tests). These three months are commonly known as the "window period". This is the reason why, if you think you may have been recently exposed to the virus, you should wait three months before having an HIV test to make sure what your HIV status is. Some doctors recommend that you go and test again after 6 months.

Another test is available that can tell you whether you in fact have **HIV** in your blood, not just the antibodies. This test is called a PCR test and is more expensive than the ELISA or Western Blot tests. With the PCR test the virus can be detected within 12 days after exposure to HIV.

3 The benefits of knowing your HIV status

Knowing your HIV status is important. If you do not have HIV, you can make sure that you take more care not to contract HIV in the future. If,

however, you have HIV, it allows you to take control over how you deal with your HIV.

Dealing with having HIV

Some steps that can help you deal with your HIV status include:

- Living a more healthy life by eating a balanced diet and getting lots of exercise;
- Planning properly for your future;
- Finding out what treatment is available and what you can afford;
- Finding out what you can do to afford better treatment (for example, joining a medical aid); and
- Seeking counselling and support groups or service organisations that help people living with HIV/AIDS.

Having HIV does not mean you are about to die. You can have HIV and still be healthy and able to function as well as people who do not have the virus. This is one of the reasons why it is wrong to require people to test before employment.

While there is no cure for HIV, medical science has progressed remarkably and has made it possible for people to live longer and cope better with the disease. Some treatments, such as anti-retroviral medication, can delay or prevent HIV leading to AIDS. While many drugs and treatments may be expensive, newer and cheaper drugs are being developed all the time.

4 ... and the risks

There are little risks involved in you knowing you have HIV. Although some people have been denied employment, fired and even been physically attacked by other people because of their status, this has only happened once others have found out that they have HIV. This kind of discrimination is a result of prejudice, fear and ignorance and makes it hard for people to disclose to others that they have HIV.

NOTE

There is no shame in having HIV/AIDS and your HIV status says nothing about who you are or what you are worth.

There are laws that make it unlawful to discriminate against you because of your HIV status, including the Constitution. These are discussed briefly in this booklet.

It is also important to remember that your status is confidential (meaning only you can decide who else should know). There are both laws and policies to protect this right.

Since the benefits of knowing your status may outweigh the risks, it is to your advantage to find out what your HIV status is. Again, the decision to have an HIV test is yours and yours alone and, except in very rare cases, you **cannot** be forced to take an HIV test. In other words, you have the right to decide. Even while this is the case, the AIDS Law Project has heard of many cases where this right is violated.

5 Common examples of violations

a. When applying for a job

Often employers ask people applying for a job with them to take an HIV test. The Employment Equity Act says this is **not** allowed, except if your employer has gained permission from the Labour Court to do so, or if you apply for a job with the South African Defence Force (SANDF), the National Intelligence Agency or the Secret Service. Some employers try to get around this by asking people to fill in a "health questionnaire", which usually asks whether or not you have HIV. This, too, is not allowed. If you are asked to have an HIV test or to fill in a questionnaire, you can refuse to provide information about your HIV status.

b. At work

In some cases, workers who have HIV have been dismissed, demoted or denied their employee benefits. The law (and recent policy) on the rights of workers makes it quite clear that employers may **not** discriminate against workers who have HIV.

Domestic workers often suffer from this practice, especially when they are responsible for childcare. Domestic workers have the same rights as other workers and the AIDS Law Project has successfully defended their rights in many such cases.

c. When applying for medical aid

Medical aid schemes used to refuse to take people who were already sick or they could make them pay more than other people. Often, medical aid schemes would refuse to pay for any medicine or treatment related to HIV, or they would have limits on how much they would pay. Some medical aids would only allow R100 per year for anything related to HIV!

In terms of the Medical Schemes Act (No 131 of 1998), this is no longer allowed. Medical aid schemes must now accept anyone who wants to join them as long as the person can afford the contributions. The premiums (the amount you have to pay) are based on how much you earn and how many people you wish to register as dependents and not on whether you are sick.

So, if you have HIV, you can still get medical aid and the fact that you have HIV makes no difference to how much you have to pay. For this reason, you do not have to have an HIV test when you apply for membership to a medical aid scheme.

d. In hospital, at clinics and when visiting your doctor

While you are visiting your doctor or are a patient in hospital or at a clinic, you have the same rights as anyone else. **You may not be tested without your consent.** Even so, the AIDS Law Project receives many complaints of this kind and has defended people and lodged complaints against doctors in such cases.

It is important to remember that, if you agree to have a test at a hospital, clinic or at your doctor, the person who does the test is not allowed to tell anyone the result except you.

CASE-

In one AIDS Law Project case in 2000, a doctor tested a person without his informed consent. Rather than go to trial, the doctor agreed to pay damages to this person. Similar cases are still being dealt with. The AIDS Law Project has lodged several complaints with the Health Professions Council of South Africa.

6 Insurance

When applying for life insurance

Some insurance policies do not require you to have an HIV test, but these policies only give very low cover. Usually, insurance companies will ask you to have an HIV test when you apply for life insurance. **You cannot be forced to have an HIV test** but if you refuse to have one, they will probably not give you life insurance.

If you do agree to have an HIV test, the insurance company must follow all the rules of HIV testing. This means you must be given pre-test and post-test counselling to make sure you know what the test is about and what the consequences of testing HIV positive may be. Also, the results of your test must be treated with confidentiality. This means that your right to privacy must be respected and the result of your test may not be given to anyone else unless you agree to this.

6 Common law, legislation and policies

South African law is made up of two main parts, **common law** and **legislation**, both of which are equally important and have to be followed by everyone.

The common law, legislation and policies have been developed to stop violations on the grounds of HIV status and to set out the rules around HIV testing.

Common law is laws and rules that have been passed down over the years without having to be written down. It includes things like the crimes of murder and theft.

Legislation is written law. Because the common law comes from long ago, governments write new laws to cover new situations. These written laws are known as **Acts**.

Policies are **not** laws. They are **guidelines** that **should** be followed by everyone. They are often based on laws and can become law in time. If a Judge in a court case uses a policy to reach a decision, it becomes law. If the government sets the policy, all government employees must follow it.

7 The law on HIV testing

a. The common law rule on informed consent

Testing for HIV is a medical procedure and the common law says a medical procedure can only be done on you if you **consent** (agree) to it. This was decided in a very old case from 1922, known as **Stoffberg v. Elliot (1023 CPD 148)**.

To say that you have consented to a test, you must know what it is you are agreeing to and must actually agree to it. This is called **informed consent** and, as will be seen, there are very few cases where a test can be done on you without your informed consent.

To make sure your consent is informed consent, policies dealing with HIV testing all say you must be given **pre-test** and **post-test counselling**.

The decision in **Stoffberg v Elliot** has been followed in many cases, including **Castell v de Greef** and **C v Minister of Correctional Services**. Even so, people are **still** tested without their consent. This is why new laws and policies have been put in place.

Case

Castell v De Greef
1994 (4) SA 408 (C)

- In this case, the judge said that in order for consent to exist, a person must:

- Know the nature and extent of the harm or risk;
- Have **understood** the nature and extent of the harm or risk;
- Have agreed to the harm or risk;
- Have agreed to **all parts** of the harm or risk, including the consequences.

b. Legislation - The Constitution and the Bill of Rights

The Constitution (which contains the Bill of Rights) is the highest law. This means everyone has to follow it and no laws may go against it.

The most important human rights with regard to HIV testing are:

- **Freedom and Security of the person** - You have the right to "bodily integrity", which means you decide what happens to your body. So, you cannot be forced to take an HIV test. You also have the right not to be made part of a medical experiment unless you give your informed consent. This means you must know what will be done to you and what the consequences will be for you.
- **Privacy** - Your privacy must be respected. Only you can decide who should know the result of your HIV test.

8 Policies on HIV testing

a. Health Professions Council (HPC) Guidelines on the Management of Patients with HIV infection or AIDS

The HPC (previously called the South African Medical and Dental Council or the SAMDC) was set up by Parliament. All doctors have to belong to it and if a doctor breaks the rules set by this body, a complaint can be made to the HPC. The HPC has the power to discipline doctors, including not allowing them to practice medicine anymore.

These guidelines were written by the SAMDC to advise doctors on how to deal with patients with HIV/AIDS. These guidelines say clearly that HIV testing can only be done with your **informed consent**.

To make sure you know what you are consenting to, doctors must give you **pre-test** and **post-test counselling**.

Pre-test counselling

Doctors must **discuss** the test with you or must arrange for you to discuss the test with a counsellor before you are tested.. During this discussion, they must explain:

- What the purpose of the test is (that is, that the test is to see whether you have HIV);
- The advantages and disadvantages of testing;
- What effect the result of the test will have on treatment you will be given; and
- How to cope with a positive test result (such as who to tell, what your needs will be and what support services there are).

Post-test counselling

You must be given counselling when the result of the test is given to you (post-test counselling). This is to help you understand and deal with a positive or negative result and includes discussing the following issues:

- What health care facilities and other support structures there are to help you; and
- Who can help your family or sexual partner to cope.

CASE

C v Minister of Correctional Services 1996 (4) SA 292 (TPD)

In this case, a prisoner was given an HIV test. He had been told what the test was and that he could refuse. But he was not given pre-test or post-test counselling and had very little time to decide whether or not to have the test. When he found out he had HIV, he sued the Minister for violating his right to privacy. The court agreed and said that, because he had not been given proper pre-test and post-test counselling and had little time to decide, he had not given **informed consent** to the test.

Testing without informed consent

The HPC Guidelines say that testing **without** your informed consent can only be done in the following circumstances:

Emergency

In an emergency, where it is impossible to get your consent (such as when you are unconscious). However, the AIDS Law Project believes that such testing must only be done if it is in the interests of the patient.

Needle stick Injury

Where a health care worker has been exposed to a possible risk of HIV infection, such as where they have pricked themselves with a needle that has already been used. Because there are antiretroviral medicines (known as post-exposure prophylaxis or PEP) that may prevent HIV infection, the guidelines say the health care worker should be able to find out what your HIV status is if the needle was first used on you.

- If you refuse to give consent to an HIV test after a needlestick injury and if there is already a sample of your blood available, it can be tested, even if you don't give your permission. If you would like to know what your HIV status is, you must be given counselling before you are given your result.
- If there is no blood sample available, you can be asked to give a sample. If you refuse, the health care worker must ask the Medical Officer of Health to agree to this being done and blood can be taken from you.

Comment

The ALP does not agree with HIV-testing without consent. This is because a person could be in the window period and a negative test result would not prove anything. Instead, we recommend that health care and emergency workers are counselled about the possible risk of infection and that all cases of possible exposure are treated as if the person had HIV. That is, they should be offered post exposure prophylaxis.

Post exposure prophylaxis

These are antiretroviral medicines (like AZT) that can be taken to reduce the risk of someone being infected with HIV if they have recently been exposed to the virus. They **must** be taken within 3 days of being exposed to risk.

What if you cannot consent?

Where you cannot consent to a test (for example, if you are too young or you are unconscious) someone else may do so for you. This "**proxy consent**" is consent by a person who is legally entitled to give consent on behalf of another person - for example, a parent or guardian of a child below the age of 14 years.

b. The National Policy on Testing for HIV

This policy has been developed by the Department of Health.

Government health care workers must follow it. This policy also provides useful guidance to private doctors and health workers, employers and people employed outside of government.

According to this Policy **informed consent** is required for testing, for example when:

- You ask for a test;
- A doctor says you should have a test;
- The test is for research purposes; or
- The test is done to screen blood being donated. However, if you do not give consent to this, you will not be allowed to donate blood.

To make sure your consent is informed consent, the Policy says you must be given pre-test and post-test counselling. The rules here are very similar to those in the HPC guidelines, but have more detail on post-test counselling. They say post-test counselling should involve at least two sessions and should include discussions on:

- **If the result is negative:**
 - How to reduce the risk of being infected with HIV; and
 - That the test might be negative if you are still inside the window period.
- **If the result is positive:**
 - What this means for you and your family;
 - How to deal with difficulties you may encounter;
 - Who you would like to tell about the result; and
 - What medical care you need and how to get it.

Testing without informed consent is not allowed as set out in the HPC guidelines (see pages 13-14) but this Policy includes provisions for testing for “epidemiological purposes”. Even though informed consent is not required here, the testing must be unlinked and anonymous (for example, your name must not appear on the blood sample).

HIV testing for “epidemiological purposes” means testing to get information about the distribution of HIV infection in society so that this information can be used to prevent and control HIV infection.

This Policy says you can never be tested as a matter of routine in hospitals or clinics, even if you consent to it. This is to stop hospitals testing all patients regardless of why they are there.

You may only be tested for HIV when applying for a job if the Labour Court has granted an employer permission to carry out testing.

**c The South African Medical Association (SAMA)
Human Rights and Ethical Guidelines on HIV: A Manual for
Medical Practitioners**

SAMA can be seen as a type of trade union for doctors. Its membership is voluntary and it has no statutory or disciplinary powers. At present some 70% of doctors in both the public and private sectors are members of SAMA.

The SAMA manual draws on the HPC Guidelines as well the World Medicine Association’s International Code of Medical Ethics and other documents. It provides detailed guidance to medical practitioners on pre-and post-testing counselling, informed consent, confidentiality, access to treatment, certificates and other topics.

Post-test counselling

On Post-test counselling, the Manual notes that the duty to provide post-test counselling falls on the medical practitioner who commissioned the HIV test. This means that you have to get post-test counselling from the person who asked for the HIV test to be done. The practitioner cannot shift the duty to others by just referring the patient to a counselling service.

Home-tests

There are home-test HIV kits available from pharmacies, which do not require pre-and post-test counselling. While these kits may be convenient, the effectiveness and reliability of these tests in detecting HIV anti-bodies may vary. It should also be noted that pre- and post-test counselling are very important components of finding out one's HIV status. These procedures help people understand the HIV-test itself and other aspects of testing such as the window period. They also assist people in coping with their HIV-status. The AIDS Law Project recommends that people who want to use these home-test kits, discuss it with their doctors first and/or seek the services of a counselling organisation before using the test. We would also like to point out that employers are not allowed to test their employees for HIV without permission from the Labour Court, and this includes the use of home-test kits (see page 8).

SAMA notes that a medical practitioner must inform the patient of the reliability of a home-test if the patient tells the practitioner that she/he has taken such a test. The practitioner should encourage the patient to undergo a second test and the practitioner should adhere to all other principles relating to good patient care even if the patient refuses to take a second test. SAMA notes that it is likely that the duty to provide post-test counselling to the patient may fall on the practitioner, even though the practitioner did not ask for the test to be performed on the patient.

9 Enforcing your rights

Note -
the addresses of organisations mentioned below can be
found on pages 22 & 23

Testing without your informed consent is an **assault**, and you can lay a **charge with the police**. You can also **sue** (bring a case against) the person.

If a doctor tests you without your informed consent, you can lay a complaint with the **Health Professions Council**.

If a nurse tests you without your informed consent, you can lay a complaint with the **South African Nursing Council**.

You can also contact an NGO, like the **AIDS Law Project**, for help.

Glossary

The following terms are often used when people talk about HIV and AIDS:

HIV

Human Immunodeficiency Virus that causes AIDS.

AIDS

Acquired Immune Deficiency Syndrome. This means the body cannot fight infections because the immune system is weakened.

Antibodies

These are produced by the **immune system** to fight against the causes of disease.

Anti-retroviral drugs

Drugs that reduce the rate that HIV spreads through the body. Use of these drugs is known as anti-retroviral therapy.

Immune System

The body's way of fighting infection and disease.

Opportunistic Infections

Infections that people with HIV or AIDS get because their immune system is weak.

Sero-conversion

When your body makes anti-bodies to fight HIV, this is called "sero-conversion". After this, an HIV test will give a positive result. Sometimes people get sick when this happens (sero-conversion illness). Many people don't notice and, because there are no signs, they do not know they have HIV unless they have a test.

Window Period

This is the period of up to 3 months between the first HIV infection and when the body makes anti-bodies to fight it (when sero-conversion takes place). During this time, an HIV test can give a negative result even if you are infected with HIV.

Contact Details

Health Professions Council of South Africa

P O Box 205, Pretoria 0001

Tel: 012-338-9300

Fax: 012-328-5120

Web: www.hpcsa.co.za

South African Nursing Council

P O Box 1123, Pretoria 0001

Tel: 012-420-1000

Fax: 012-343-5400

AIDS Law Project (ALP)

Center for Applied Legal Studies

University of the Witwatersrand

Private Bag 3, Wits 2050, South Africa

Tel: 011-717-8600

Fax: 011-403-2341

Web: www.alp.org.za

AIDS Consortium

4th Floor, East Wing, Auckland House, 185 Smit Street

Braamfontein, Johannesburg, 2017

Tel: 011 403 0265

Fax: 011 403 2106

Web: www.aidsconsortium.org.za



Treatment Action Campaign (TAC)

Johannesburg:

Tel: (011) 339-8421

Durban:

Tel: (031)304-3673

Cape Town:

Tel: (021) 364-5489

www.tac.org.za

KNOW YOUR HIV Status - Issues around HIV testing.
Why should you have an HIV test? What are the benefits of knowing your HIV status? What rules have to be followed by people who conduct HIV tests.

This booklet answers these and other questions.

You can get copies of this booklet from the AIDS Law Project at the following address:

AIDS Law Project
Center for Applied Legal Studies
University of the Witwatersrand
Private Bag 3, Wits 2050, South Africa
Tel: 011-717-8600 Fax: 011-403-2341
Email: alpadm@law.wits.ac.za
www.alp.org.za

The ALP gratefully acknowledges INTERFUND for sponsoring this publication.