

HUMAN AND LEGAL RIGHTS

WHAT ARE HUMAN RIGHTS?

Human rights are rights and freedoms that everyone has, just because they are human. No one can take these away from us. In South Africa our human rights are written into the Constitution and are guaranteed, interpreted and given meaning in different ways – one way is by the courts.

Progressive realisation of the right to have access to healthcare services.



The state has a duty to respect, protect, promote and fulfil human rights. Individuals, communities and other institutions (e.g. the Human Rights Commission) also have certain duties to ensure human rights. However, rights are sometimes limited because of other rights, other people's rights, or situations in which a person voluntarily gives up his or her rights. The Constitution also tells us how certain rights are limited.

WHAT ARE LEGAL RIGHTS?

Legal rights are rights that are found in the laws of a particular country. In South Africa, our legal rights come from the Constitution, statutes (Acts), common law, customary law and court decisions.

1. The Constitution
2. Customary and common law
3. Statute law (Acts)
4. Court decisions



In South Africa, **the Constitution** is our highest law and all other laws must be in line with it. We can challenge laws that go against the Constitution in the Constitutional Court as this court has the power to strike down or cancel laws that do not agree with the Constitution. When the courts interpret the Bill of Rights, they must also look at international law and may even look at the law in other countries to help guide their decisions.

Statute law includes written laws called statutes or Acts that are made or changed by Parliament – the highest law-making body in the country. Statutes can also be made by provincial and local governments.

The following Acts apply to HIV vaccine research and development:

- The *Medicines and Substances Control Act* of 1965, which, for example, says that research must be submitted for regulatory and ethical review.
- The *National Health Act* of 2003, which, for example, deals with legal aspects of informed consent and the participation of children in research.

A statute can give a person, e.g. a Minister, power to make more laws that complement or give further details to a statute. These are called regulations. The Constitution is also a statute.

Common law comes from Roman-Dutch and English law. We look to the common law for guidance when statute law does not cover a particular legal problem. The following areas of common law are important for HIV vaccine research and development:

- **The Law of Contract:** This law rules agreements between parties, for example, between trial participants and institutions running the trials.
- **The Law of Delict:** This law rules actions that harm others or their property, for example, in some circumstances, in the unlikely event that the trial participant is deliberately or negligently harmed.

The courts can develop common law or they can replace the common law with statute law so that it is in line with the Constitution.

Court decisions: When people are involved in a conflict about the law, or when someone has broken the law, they can take the conflict or the person who broke the law to the courts for a decision.



South African
Constitutional Court in
session

WHICH HUMAN RIGHTS ARE IMPORTANT TO HIV VACCINE TRIAL PARTICIPANTS?

The following rights are important to HIV vaccine trial participants:

- the right to human dignity;
- the right to equality and non-discrimination;
- the right not to be subjected to medical or scientific experiments without informed consent;

- the right to privacy and confidentiality; and,
- the right to have access to health care services.

THE RIGHT TO HUMAN DIGNITY

The right to human dignity is at the heart of the South African Constitution. Guaranteed in Section 10, this right is the foundation of many other rights such as the right to equality and the right to informed consent. It is based on the idea that we must recognise that every person has worth and value, and must be treated with dignity. Trial participants have inborn worth as human beings – they are not ‘guinea pigs’ or only there to help us find medical or scientific answers. This right is also at the heart of the draft *SAAVI Preventative HIV Vaccine Trial Participant Charter of Rights*.

THE RIGHT TO EQUALITY AND NON-DISCRIMINATION

Equality and non-discrimination are dealt with in Section 9 of the Constitution and in *The Promotion of Equality and Prevention of Unfair Discrimination Act 2000* (also called the *Equality Act*). These laws say that you cannot discriminate against anyone because of the following – race, gender, sex, pregnancy, marital status, ethnic origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

No one may discriminate against a person who is living with HIV and/or AIDS. In the same way, no one may be discriminated against because they are participating in an HIV vaccine trial or if they have a **false-positive HIV test result**. Discrimination that is related to a person’s participation in a trial is called ‘trial-related’ discrimination.

THE RIGHT NOT TO BE SUBJECTED TO MEDICAL OR SCIENTIFIC EXPERIMENTS WITHOUT INFORMED CONSENT

This right means that each person has a right to agree to participate, or to refuse to participate, in medical or scientific experiments based on a true informed consent process (see the Ethics fact sheet of this series) – this includes HIV vaccine research. This right is found in international law, in Section 12 (2) (c) of our Constitution under the right to bodily and psychological integrity, and in statute and common law.

THE RIGHT TO PRIVACY AND CONFIDENTIALITY

Section 14 of the Constitution includes the right to privacy. The common law also describes a right to privacy and a right to confidentiality. In HIV vaccine trials, we must protect a trial participant’s right to privacy and confidentiality because:

- they may fear discrimination and stigmatisation if people find out that they are part of the HIV vaccine trials; and,

- they may fear discrimination if they become HIV infected while they are participating in the trial.

Sometimes the right to privacy and confidentiality can be limited. For example, when someone decides to make certain information public by, for example, giving an interview to a newspaper.

THE RIGHT TO HAVE ACCESS TO HEALTH CARE SERVICES

Section 27 (1) (a) of the Constitution says that everyone has the right to have access to health care services. This is a socio-economic right, which means that it cannot be claimed by an individual, but must be claimed as a group because it is a collective right.

The State must take all reasonable steps to ensure that people can get access to health care services. The State also must not interfere with anyone’s enjoyment of access to health care services. HIV vaccine trial participants may need access to the following health care services:

- counselling services to get information and to talk about their fears and concerns; and,
- HIV treatment if they become HIV infected due to continued high-risk behaviour.

The above five rights are also written into the draft *SAAVI Preventative HIV Vaccine Trial Participant Charter of Rights*. Much of the Charter can be adopted to address therapeutic HIV vaccine trials and clinical trials in general. The Charter is available from SAAVI or, online, at: www.saaui.org.za.

WHO SAFEGUARDS THE HUMAN AND LEGAL RIGHTS OF VOLUNTEERS?

The rights of volunteers and HIV trial participants are safeguarded through South African law and by bodies such as the Medicines Control Council (MCC), the Research Ethics Committees (RECs) and sometimes an independent Data Safety Monitoring Board (DSMB). These bodies can, for example, pause or close a trial based on regular reviews of trial progress and/or analysis of data. Community Advisory Boards or Groups are also mechanisms to ensure that any human rights issues raised by the community are addressed.

False-positive HIV test result:

When an HIV vaccine design triggers HIV antibodies, this can cause a positive test result on a standard HIV antibody test. But no test HIV vaccine can give a person HIV. So he or she will need another kind of HIV test that tests for the presence of the HI virus itself.

