

Legal and human rights



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South African Medical Research Council

BUILDING A HEALTHY NATION THROUGH RESEARCH





What are human rights?

1. Rights & freedoms everybody has because we are humans.
2. These rights cannot be taken away from us.
3. But sometimes they can be limited by, e.g. other rights or by other people's rights.





How are our human rights ensured?

- The State has a duty to:

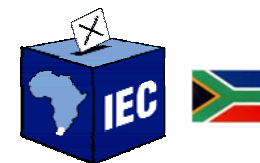
Respect human rights	Protect human rights	Promote human rights	Fulfil human rights
<p>Not to do anything to:</p> <ul style="list-style-type: none"> • take away a person's rights or to stop them using & enjoying their rights. • unfairly discriminate against anyone, e.g. women. 	<p>Taking action to prevent a person's rights being violated or dishonoured by third parties.</p>	<p>Informing people about their rights, & explaining through workshops, radio, publications, TV etc., how they can enjoy these rights,</p>	<p>Taking reasonable e.g. legislative, financial, & judicial steps to make it possible for people to use & enjoy their rights.</p>

Individuals, communities & other institutions also have certain duties to ensure human rights.



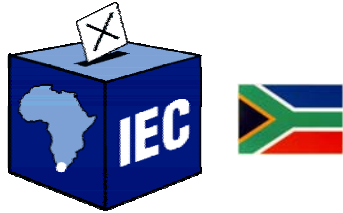
Different kinds of human rights

- Civil & political rights
 - Rights that prevent the State from doing something
e.g. the right to life prevents the State from using the death penalty
 - Also require the State to do something positive to ensure the rights
e.g. organising a voting system to ensure the right to vote
- Socio-economic rights
 - To do with people's social, economic & cultural security
 - State must not prevent people from enjoying these rights
 - State must also act to increasingly fulfil these over time
 - Collective rights. Can't be claimed by individuals
e.g. a group of people's right to housing, water, health care



Some civil & political rights

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Political rights



Freedom of
religion, belief
and opinion



Privacy



Freedom of
assembly,
demonstration,
picket &
petition



Freedom of expression



Access to courts

Civil & political rights



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- Right to equality
- Right to human dignity
- Right to life
- Freedom of security of the person
- Freedom from slavery, security servitude and forced labour
- Right to privacy
- Freedom of religion, belief & opinion
- Freedom of expression
- Political rights
- Right to citizenship
- Labour rights
- Freedom of assembly, demonstration, picket & petition
- Freedom of association
- Freedom of movement & residence
- Freedom of trade, occupation & profession
- Right of access to information
- Right to just administrative action
- Right to access to courts

Some socio-economic rights



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Right to access to health care
food, water & social security



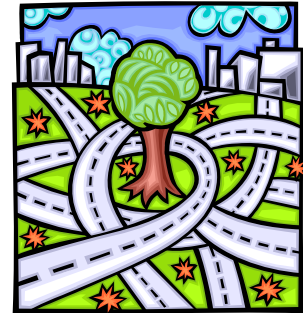
Property rights



Right to education



Rights of cultural,
religious & linguistic
communities



Environmental rights



- Environmental rights
- Property rights
- Right to housing
- Right to access to health care, food, water & social security
- Children's rights
- Right to education
- Right to use the language and to participate in the cultural life of choice
- Rights of cultural, religious and linguistic communities





What are legal rights?

They are found in the laws of a country, e.g.:




- The Constitution
- Statutes
- Common law
- Customary law
- Court decisions



Legal rights can be applied in the courts.




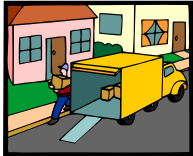


Rights important to people living with HIV and AIDS (PLWHAs)



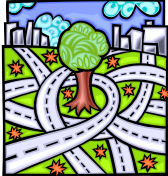

Right	What it means for PLWHAs
Equality 	Not to be unfairly discriminated against.
Human dignity 	No one may insult or damage a person's dignity by their words or actions.
Freedom & security of the person 	The right to make your own decisions about medical treatment & pregnancy. The right not to be subjected to medical or scientific experiments without informed consent.

Many of the rights that apply to PLWHAs also apply to HIV vaccine trial participants.






Right	What it means for PLWHAs
Privacy 	No one can force you to disclose information, e.g. your HIV status.
Freedom of expression 	You are free to get & give ideas & information e.g. about HIV & AIDS.
Freedom of association 	You can join any organisation you choose.
Freedom of movement & residence 	You are free to move around and in & out of the country. You cannot be forced to live in a separate place.


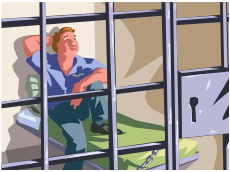


Right	What it means for PLWHAs
Freedom of trade, occupation & profession 	You can choose what kind of work you want to do.
Labour relations 	You may not be unfairly discriminated against at work.
Environment 	PLWHAs have a right to a healthy environment even if in prison or hospital.
Housing 	PLWHAs may not be refused a subsidy or loan to buy a house, or be evicted due to their health.



Right	What it means for PLWHAs
<p>Health care, food, water & social security</p> 	<p>PLWHAs may not be refused treatment by doctors/hospitals. They have a right to a Disability Grant if too ill to support themselves/their family.</p>
<p>Education</p> 	<p>PLWHAs have the same right to education as everyone else. A school cannot refuse to educate you because you have HIV or AIDS.</p>
<p>Access to information</p> 	<p>e.g. You can ask to see any policies that may discriminate against you, and can challenge them in court.</p>

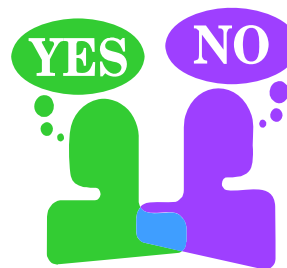


Right	What it means for PLWHAs
<p>Just administrative action</p> 	<p>If you think that you are being refused a social service, e.g. education, for unjust administrative reasons, you have the right to demand to see the reasons in writing.</p>
<p>Arrested, detained & accused persons</p> 	<p>Prisoners cannot be treated in a discriminatory or undignified way because of their HIV status.</p>



Rights relevant to HIV vaccine trial participants?

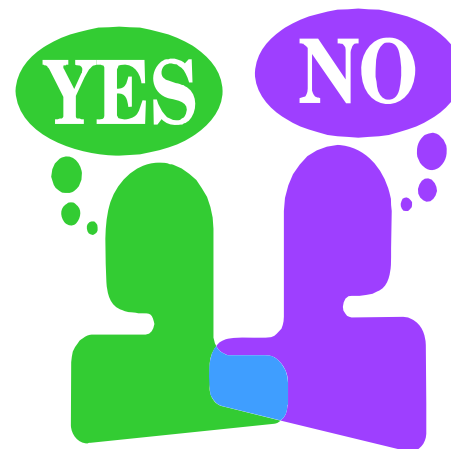
1. The right not to be subjected to medical experiments without informed consent.
2. The right to privacy & confidentiality.
3. The right to equality and non-discrimination.
4. The right to human dignity.
5. The right to access to health care services.





The right to not be subjected to medical or scientific experiments without informed consent

- Bill of Rights, Section 12 (2) (c)
- Each person has a right to agree to participate or to refuse to participate in medical experiments and trials.





Informed consent is **ethical** if:

1. Get full information & time to think about it - to make a good decision.
2. Volunteers understand the information.
3. They consent freely - no undue influence.
4. Volunteers must have legal & factual capacity to consent.
5. It is explicit – recorded in writing or another acceptable way.

In common law IC is **legal** if:

1. Legal capacity– e.g. volunteer is of legal age.
2. Factual capacity – s/he understands the facts.
3. It is lawful – not against the law, public policies or the Constitution.
4. The person has full information.
5. They consent freely & voluntarily.
6. They are told they have freedom to withdraw.

Draft regulations of the *National Health Act* now give more detail on IC.

The right to privacy and confidentiality

1. Our Bill of Rights in the Constitution (Section 14) includes the right to privacy.
2. The Common Law describes the right to privacy & a right to confidentiality.
 - We all have this right. It applies to participation in an HIV vaccine trial, about our HIV status, etc.
 - You cannot be forced to disclose this information. Disclosure should be voluntary & free.





When is the right to privacy & confidentiality limited?

- If a person decides to make information public.
 - e.g. they speak to the newspaper about their trial participation.
- If certain sensitive information comes up in counselling, the counsellor should report it to the appropriate authorities.
 - e.g. about abuse of women or children.
- If someone is at risk of harm & it can be avoided.
 - e.g. a trial participant is HIV infected & tells a counsellor that he/she will not tell his/her sexual partner, or practice safe sex.
 - after trying different ways to solve the problem, as a last resort, the counsellor decides to tell the participant's sexual partner.



The right to equality & non-discrimination

- The Constitution (Section 9) & the Equality Act (2000) list grounds on which it is illegal & unfair to discriminate against anyone.
- These grounds include:
 - race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.
- Not all discrimination is unlawful or unfair e.g. those not medically suited to HIV vaccine trials.





The right to human dignity

- Central to the South African Constitution.
- Section 10 of the Bill of Rights.

Why is dignity so important?

- Based on the idea - we need to recognise that every person has worth & value.
- Foundation for many other rights.
 - e.g. the right to Equality, Section 9 of the Bill of Rights.





The right to have access to health care services

- Section 27 (1) of the Constitution
- Socio-economic right - collective right.
- The State must not interfere with anyone's enjoyment of health care services.
- The State must also take reasonable steps to progressively realise this for everyone in South Africa, within its resources
 - May include passing legislation, or other measures.
 - State must also draw up a plan & implement it to realise this right for everyone.



Why protect an HIV vaccine trial participant's right to privacy & confidentiality?

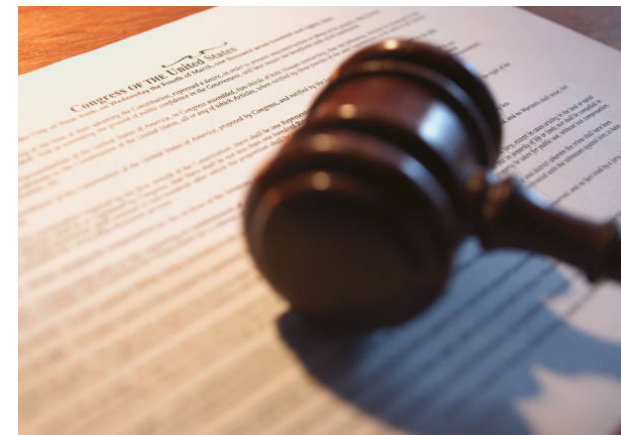
- They might fear stigmatisation & discrimination due to:
 - Trial participation.
 - If they become HIV-infected during the trial.





What is a Charter?

- A document that sets out people's rights in a certain situation e.g. an HIV vaccine trial.
- May not be legally binding, but should describe the legal basis of the Charter
- The Department of Health has adopted a *Patient Rights Charter*
 - to help support, promote & protect everyone's right to access to health care services.





The draft *SAAVI HIV Vaccine Trial Participant Charter of Rights*

- Preamble (Introduction and background)
 - Background & introduction.
 - What subscribers agree to, recognise & commit themselves to.
 - Legal & constitutional basis.
- Section 1: Informed consent
 - Volunteers must give IC to participate.
 - Type of information to be given.
- Section 2: Non-discrimination and human dignity
 - Rights of trial participants to be treated with dignity & not to be discriminated against.



The draft *SAAVI HIV Vaccine Trial Participant Charter of Rights*

- Section 3: The right of access to health care services
 - Every trial participant's right to have continued free access to health care services during the trial e.g. counselling, testing & treatment.
- Section 4: The right to privacy
 - Right to privacy & to have information about them kept confidential.
 - When this right can be broken.
 - Identification to confirm trial participation. No confidential information given without the participant's informed consent.
- Responsibilities of trial participants
 - With rights come responsibilities.
 - To keep others' participation confidential, not to donate blood during the trial etc.